

**The 'arts' as cultural intervention
for people with learning
disabilities: A voluntary sector
'community' initiative in south-east
London**

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Abstract

This thesis examines 'cultural intervention' by arts practitioners/social activists in inner city London, England, in the lives of adults who have 'learning disabilities'. 'Cultural intervention' is thought necessary largely in response to their social and cultural exclusion. This has been highlighted by recent shifts in social policy, particularly those of the NHS and Community Care Act 1990. An anthropological critique of social policy and welfarism as related to people with learning disabilities in Britain is offered, questioning the existence of 'community' at an ideological and material level. Also, the role of the 'arts' as an arena in which social and cultural attitudes can be challenged is explored.

This is achieved through the study of relevant theoretical literature, drawing on anthropology and performance and disability studies, combined with analysis of fieldwork data collected in an arts company, Entelechy, between January 1997 and April 1999. Consequences of social policy on the lives of people with learning disabilities are (indirectly) explored through their participation in 'performance' (including drama, dance and music); visual and tactile media; and narrative, based in workshops.

Issues around representation, subjectivity and corporeality are addressed. Qualitative anthropological methods were utilised, specifically participant observation and interviews, in addition to non-traditional techniques, as the work of Entelechy encompasses a wide range of people, including those with poor communication skills. Additionally, the research demonstrates that behaviour labelled as 'pathological' by the medical profession is often a powerful form of protest, meeting participants' needs.

Entelechy's work is contextualised within alternative arts movements incorporating the avant-garde and community theatre. This runs in opposition to the employment of art as 'therapy' by some 'professionals' working with learning disabled people, who emphasise pathology and rehabilitation towards a 'normative' state, rather than creative ability or cultural expression. A unique cultural experiment is thus examined, creating arenas for dialogue.

Contents

| | Page number |
|---|-------------|
| Chapter 1: Introduction | 10 |
| i) Aims and Objectives | 10 |
| ii) Anthropology and Learning Disability | 15 |
| iii) Social Policy and Learning Disability | 18 |
| iv) Context of Research | 20 |
| v) Researching with People who have Learning Disabilities | 25 |
| vi) Access and Methods | 30 |
| vii) Chapter Outlines | 35 |
| Chapter 2: The Normal and The Abnormal: Alterity and The Formation of The 'Incompetent' in Western Discourse | 39 |
| i) Introduction | 39 |
| ii) The Normal and the Abnormal | 44 |
| iii) Normalisation: Hegemonic Discourse and the Possibilities for Transformation | 57 |
| iv) 'Keeping it (corpo)real' | 66 |
| v) Aiding the 'Incompetent' through Cultural Intervention | 82 |
| Chapter 3: 'Cultural Intervention' in 'The Community': Welfarism, Learning Disability, and 'the Arts' | 86 |
| i) Introduction | 86 |
| ii) <i>The Community</i> | 87 |
| iii) Anthropology and Community | 87 |
| iv) The 'Rational Community' | 89 |
| v) Community Care | 93 |
| vi) Cultural and Political Interventions in <i>The Community</i> | 98 |
| vii) Community Development and the Arts | 102 |
| viii) Community Arts Interventions in the London Docklands | 106 |
| ix) Entelechy: Working at the Cross-Roads Between Social Policy and 'Culture' | 111 |
| Chapter 4: Transformations: Disability, 'Art' and 'Life' | 116 |
| i) Introduction | 116 |
| ii) 'Art' and 'Life' | 117 |
| iii) Tragedy | 120 |
| iv) Performance Art: an Arena for the Exploration of Possibilities | 128 |
| v) Entelechy's 'Happenings': a) 'Untitled' and 'Coincidences' b) Incredible Journeys | 132 |
| vi) Discussion of the 'Happenings' | 143 |
| vii) 'Primal' art: 'Rationality', 'Choice' and Sonia's dress | 147 |
| viii) Beyond Therapy | 151 |
| ix) Emergent Realities | 158 |
| x) Performance Efficacy | 159 |
| xi) Conclusion | 166 |

| | |
|---|----------------|
| Chapter 5: Dance and Movement Work with People who have Profound and Multiple Disabilities: Expanding aesthetics/exploring the sensorium | 168 |
| i) Introduction | 168 |
| ii) Emotions in Movement | 171 |
| iii) Exploring tactility through contact improvisation | 174 |
| iv) The Ambient Jam Workshops | 177 |
| v) The Diamond Group | 187 |
| v) Discussion and analysis of the workshops | 191 |
| vi) Between Two Worlds | 194 |
| vii) Exploring the Sensorium: a) 'Touch' b) Music | 195 |
| Chapter 6: Subversion and the 'Inner Idiot': Protest and Conformity in Day Centres and the Drama Group 'Weaver' | 210 |
| i) Introduction | 210 |
| ii) Fieldwork context | 215 |
| iii) Relationships and intimacy | 220 |
| iv) Gail | 222 |
| v) Poetry | 229 |
| vi) Performance | 237 |
| vii) Conclusion | 238 |
| Chapter 7: Rediscovering Our Selves | 242 |
| i) Introduction | 242 |
| ii) Ethnographic setting | 246 |
| iii) Disability discourse: ontological, public and metanarratives | 254 |
| iv) Memory and identity in the 'recovered' lives of people with learning disabilities | 260 |
| v) First hand accounts | 269 |
| vi) The pilot study | 283 |
| vii) Crafting Our Memories | 292 |
| viii) Conclusion | 305 |
| Chapter 8: Conclusion | 311 |
| i) Final Reflections | 311 |
| ii) Suggestions for Future Research | 329 |
| Appendix | 332 |
| I - Breakdown of group membership of weekly groups. | |
| II - Classifications of 'mental Retardation' | |
| III - Advocacy | |
| IV - Makaton - an augmentative communication system | |
| V - Foucault – a history of madness | |
| VI - Itard and Seguin | |
| VII - Welfare State International | |
| VIII - Dartington Conference Report | |

- IX - Breakdown of Between Two Worlds' Participants
- X - Dadaism
- XI - John O'Brien's Five 'service accomplishments'.
- XII - Crafting Our Memories - aims and objectives
- XIII - Entelechy and the Avant Garde
- XIV - Fact and fiction in learning disability narrative - viewpoint of ROH co-ordinator, Mara de Wit.

Glossary 349

Bibliography 350

Illustrations:

- A – Weaver 'members' rehearsing a performance** 9
- B - Weaver 'member' rehearsing a performance** 374
- C - Self-portrait by Mike, taken from his lifebook** 375
- D - Self-portrait by Mike, taken from his lifebook** 376
- E - Page from George's lifebook, depicting his 'remembered' family** 377
- F - Page from Tom's lifebook depicting the garden at Darenth Park.** 378
- G - Dough sculptures made in Crafting Our Memories group** 379
(photograph by Phil Polglaze)
- H - George's 'family tree' made out of dough** 380
(photograph by Phil Polglaze)

Foreword

List of key informants:

Core team members of Entelechy Arts period 1997 - 1999:

David Slater - Company Director

Rebecca Swift - Combined Arts Co-ordinator

Mara de Wit - Co-ordinator of Rediscovering our Histories Project

Pam Martin - Co-ordinator of Advocacy Project

Peter Jarman - Apprentice arts practitioner

'Jane' - A woman with profound and multiple disabilities who was often employed as a trainer

Sessional artists:

Charles Hayward - Musician

Laura, Siobahn and Kate - dancers

Occasional invited artists:

Karen Barnet - visual artist

Ernst Fischer - performance/live artist

Volunteers:

Hazel - dance and movement.

Paul - support worker/paid trainer

'Members' - People who had learning disabilities who took part in Entelechy's activities

There were too many people to list individually here, but they are mentioned throughout the thesis, usually under pseudonyms (except where explicitly stated). A list of members of most of the workshops can be found in Appendix I.

Permission was obtained from Entelechy facilitators to use their real names. As their work is very unique, it would be easily recognised by others working in this field. I have used all the real names of Entelechy practitioners and invited artists. However, I have disguised the identities of nearly all of the learning disabled 'members', using pseudonyms, except where explicitly stated. This is because of the issues around 'informed consent', discussed in Chapter 1. Additionally, some place names, such as day centres, have also been changed for the same reasons.

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The views expressed in this thesis are those of the author, and do not necessarily reflect the views of the funding body or research participants.

*As Director of the Clinic of Charenton
 I would like to welcome you to this salon
 To one of our residents a vote
 of thanks is due Monsieur de Sade who wrote
 and has produced this play for your delectation
 and for our patients' rehabilitation
 We ask your kindly indulgence for
 a cast never on stage before
 coming to Charenton But each inmate
 I can assure you will try to pull his weight
 We're modern enlightened and we don't agree
 with locking up patients We prefer therapy
 through education and especially art
 so that our hospital may play its part
 faithfully following according to our lights
 the Declaration of Human Rights
 I agree with our author Monsieur de Sade
 that his play set in our modern bath house
 won't be marred
 by all these instruments for mental and physical
 hygiene
 Quite on the contrary they set the scene
 For in Monsieur de Sade's play he has tried
 to show how Jean-Paul Marat died
 and how he waited in his bath before
 Charlotte Corday came knocking at his door*

Coulmier's prologue from Peter Weiss' *Marat/Sade*

A



Chapter One

Introduction

The arts have always had a role to play in the changing life of social communities. They are a cornerstone of all cultures and can be viewed as a significant indicator of the general social, physical and intellectual 'health' of any culture.

B. Warren 1997: 273-4

Ultimately all of the arts provide a means by which each individual may express an inner world through symbolic means ... While the individual participating in creative activity may not always be able to control changes, at least they are able to express their reactions to them. It is this capacity of artistic activity to enable the participant to express their response to change that has led in part to the realization that participation in creative activities is important to the general health of individuals in advanced, technological cultures.

Ibid: 274

Disabled people can produce mainstream sounds ... if you get into the aesthetic ... manipulate and change it ... it can enable people to be more a part of society by doing that.

Charles Hayward, Musician

i) Aims and Objectives

This thesis seeks to document a unique cultural experiment: the conjuncture of social policy, liberalism, idealism, and the creative imagination converging at a particular time and place, namely south-east London in the 1990s. The arts company at the centre of this conjuncture, Entelechy, believed passionately in the human rights of people with learning disabilities, aiming, often through experimentation, to assist in giving articulation to their needs and wants. This did not always occur without controversy and ambiguity. It is both as a participant and an observer in their 'happenings' that I relate my fieldwork experiences (collected between January 1997 and April 1999), and give first hand accounts of my informants' views, contextualising this within theoretical and historical discourses. Additionally, analysis and interpretation is offered, asserting the integrity of the learning disabled population as social and cultural persons,

interacting with, subverting and often overriding the discourses which seek to constrict and contain them.

I examine the role, impact and outcome of this ‘cultural intervention’ in the lives of adults who have ‘learning disabilities’. The intersection of the fields of performance/creative arts and service provision for this sector of the population is explored, extending the investigation beyond ‘therapeutic’ paradigms. This entails an exploration of how the aesthetics of post-modern ‘performance’ interplay with disability politics, and how the practice of an arts company working with people with learning disabilities (Entelechy) is related to the wider cultural quest for subjectivity and identity.

Additionally, the category ‘learning disability’ and its implications and repercussions for people classified as such in contemporary Britain is explored, specifically looking at the consequences of institutionalisation, and associated social and cultural exclusion. The documentation of the lives of such people through creative means, utilising various forms of ‘narrative’, is investigated. The thesis looks at new approaches to collecting ethnographic data when working with an extremely marginalized and excluded sector of the population, many of whom do not use conventional cultural modes of communication. In particular, the role of the ‘arts’ is examined, specifically dance and movement, as a potential mode of communication for people who are non-verbal and/or profoundly disabled, i.e. exploring the idea of ‘embodied communication’.

Behaviour often labelled as ‘pathological’ by the medical profession is examined, looking at it instead in social and cultural terms, namely as a form of protest and/or

resistance by people with learning disabilities against undesirable treatment in their lives (focusing on statutory services); and how this is (or is not) facilitated through their involvement in the creative arts.

An anthropological critique of social policy and welfarism as related to people with learning disabilities in Britain is offered, questioning the existence of *community*¹ at an ideological and material level, and the consequences of the juxtaposition of the terms ‘community’ and ‘care’. At the same time the role of the ‘arts’ as an arena in which social and cultural attitudes can be challenged is examined. The mediation between macro-social processes and individual subjectivity are thus addressed.

These aims and objectives are pursued throughout the thesis, drawing on relevant theoretical literature from anthropology, performance, and disability studies, combined with analysis of fieldwork data.

The research focuses on a specific group of informants who were actively engaged in activities with Entelechy, namely, a small caucus of arts practitioners (without disabilities), and a large group of approximately eighty people², who had been labelled

¹ The word *community* is placed in italics to emphasise the fact that it is not a stable concept and is subject to multiple interpretations.

² See Appendix I for breakdown of group membership of some activities.

as having a ‘learning disability’ of some kind. This latter group, in common with people with learning disabilities living within British society as a whole, experienced (often extreme) social exclusion and marginalisation, in addition to having their lives largely organised, curtailed, and constrained by social policy (in the formation of which they played no part³).

This thesis addresses their current situation, and examines some of the historical, social and cultural influences in British society that have affected this ‘learning disabled’ population as a whole. ‘Learning disability’ is a current term used by care professionals in Britain to refer to a very heterogeneous group of people who have been assessed as having a very low ‘intelligence’⁴, previously referred to as ‘mentally handicapped’ or ‘mentally retarded’⁵. This group is largely perceived as dependent, therefore relying on others for the articulation of their needs and wants. Consequences of social policy on the lives of people with learning disabilities are (indirectly) explored through their participation in ‘performance’ (including drama, dance and music), visual and tactile media and narrative, based in workshops. Such ‘cultural interventions’ by arts practitioners aimed to bring about improvements in the lives of this learning disabled population; for example, by easing transitions from institutions to ‘community care’, building and reinforcing social networks and increasing confidence and social skills.

³ Recent moves within service provision towards self-advocacy and ‘user empowerment’ are acknowledged, although their impact is not widely documented, apparently remaining largely rhetorical in most statutory settings explored during my fieldwork. I witnessed a protest made by a self advocacy organisation in the area where my fieldwork was conducted, where leaflets were handed out critical of Social Services, whom they felt had not consulted with users of their services when implementing change.

⁴ ‘Intelligence’ is a nebulous and context specific term which can be taken to mean as being ‘endowed with the capacity of reason’ (Chambers English Dictionary).

⁵ See Appendix II for clinical classifications of this population in Western medicine and psychology.

There are more than one million people in Britain who have some form of learning disability, 190,000 of whom have severe learning disabilities (Young 1995:259). Not only does this group of people compose a significant minority but, as an externally imposed cultural and social grouping (they rarely identify themselves as ‘incompetent’), they present very interesting and salient issues. For example, people with learning disabilities are so named because they are perceived as having difficulty understanding the rules of interaction. In order to take part in the social world, they have what Goffman calls the ‘social order’ reinforced constantly by their non-disabled peers: A ‘social order’ can be defined as ‘the consequence of any set of moral norms that regulates the way in which persons pursue their objectives’ (Goffman 1963b:8). Other important issues involving this group are those regarding personhood (and, by implication, ‘the mind’ and consciousness), power and subversion, representation, communication, sexuality, social exclusion and stigma. These issues, and others, are addressed throughout the thesis through a combination of theory and fieldwork.

In many respects, this study is unique. Until relatively recently, only a few ethnographic studies had been carried out with people with learning disabilities by anthropologists, the majority of which were conducted with the most able members of this group. This thesis addresses the ‘lived experience’ of a group of people with learning disabilities who had a very wide range of abilities, many of whom were profoundly disabled, and perhaps could be considered as ‘outside’ of ‘culture’. As T.Booth, drawing on the work of Spradley argues:

A good informant should be thoroughly 'enculturised' whereas lore and language have long depicted people with learning difficulties as less than fully human.

T.Booth 1996: 238-9

In this thesis, the common factor bringing these learning disabled people together was their participation in creative arts, focusing on the activities of Entelechy in the late 1990s. Although several years after its official implementation, this was a period during which the social policy of 'community care' was still unevenly applied in some parts of the country, with responses often varying between local statutory services⁶.

ii) Anthropology and Learning Disability

Within medical anthropology, until fairly recently, much more attention has been focused on physical impairments than mental impairments such as learning disability. The reasons for this are perhaps because of the assumed problems and ethics of applying traditional research methodologies to this sector of the population⁷.

The anthropologist Edgerton (1976, 1979, 1985, 1993) has been something of a pioneer in the field of learning disability, trying to formulate cross-cultural questions about disability and deviance. Additionally, anthropologists such as Langness and Levine (1986) have used life history research to study aspects of the lives of people with learning disabilities in the USA. Jenkins (1989, 1990, 1991, 1993, 1996, 1998) and

⁶ Whether the effectiveness of 'Community Care' has improved at the beginning of the 21st Century is highly debatable. A recent government white paper (March 2001) from the Department of Health, entitled 'Valuing People' presents a 'New strategy for Learning Disability'. The paper is based on recent research commissioned by the Department of Health, which suggests that no one model of care is best for adults with learning disabilities. It argues that all models could be good when well managed, including special villages and smaller communities, and all had some advantages. Potentially, this finding will prove controversial, as it goes against entirely 'community-based' care and the move towards 'integration'.

Davies (1997, 1998a, 1998b) have researched, among other things, the transition to adulthood of young people with learning disabilities in England and Wales, and categories of (in)competence and deviance. Additionally, Angrosino has written extensively on mental health/‘mental retardation’ policy and service delivery in the United States, largely from an interactionist perspective (1981a, 1981b, 1989, 1992a, 1992b, 1994, 1998a, 1998b).

Questions of Competence, published in 1998 and edited by Jenkins, included a wide-range of essays on intellectual disabilities or ‘(in)competence’. Drawing on ethnographic evidence from Wales, Greece, Uganda, Belize, Greenland, England and the United States, the contributors developed social models of intellectual disability, looking at local models of personhood and how the categories of ‘competent’ and ‘incompetent’ are related. Classifications are seen as best understood in the context of local social relations and networks, rather than solely as individual pathology. Jenkins asserts that: ‘it is difficult to disentangle endogenous incompetence from the impact of exogenous disadvantage of one kind or another’ (1998:225). These essays show that there is no consistency between cultures as to who is labelled ‘incompetent’ or ‘competent’, and Jenkins suggests also that we should not expect to see consistency within cultures. However, some factors are arguably identified by the contributors as human competencies cross-culturally, such as the ‘generic capacity to use and understand language’, the ‘individual capacity to construct personally satisfying identities’, ‘reflexivity’, and the ability to participate in and expand one’s local lifeworld

⁷ Historical factors have also been influential in the anthropological study of learning disabilities, as Chapter 2 illustrates.

(ibid:227). For example, Nuttall, a contributor to the volume, provides ethnographic evidence from the Inuit people in Greenland, looking at their approach to the classification of people deemed unable to look after themselves. In this particular society this is seen in terms of the inability to hunt and take one's place among a complex web of fictive and non-fictive kin relationships. Being incompetent in Inuit society is seen as a temporary or transitory state, as opposed to the permanent ascribed categories in most 'Western'⁸ societies⁹. Nuttall points out that someone who in the West would be described as 'mad', is in Greenland described as 'not quite in the right state of mind' (1998:189). The dominant Danish model of competence, which stresses success in formalised education and an ability to speak Danish, is seen as opposed to and in conflict with the Inuit model of being able to hunt and take one's place in social networks.

Lungren's work in Belize (1998) similarly shows how the post-colonial legacy of dominance of the core over periphery encroaches upon local models of competence and personhood. Lungren looks at the school system in Belize and shows how it creates incompetent and competent people down the lines of class and race.

⁸ By the term 'West', I am referring to Europe and America, although this term is often somewhat vague. Lawton has drawn attention to this fact, saying 'terms such as the West and the "Western person" are inherently problematic, because anthropologists (and others) who have used – and continue to use – these stereotypes often appear to assume that 'West' is an homogenous area characterized by uniform features.' (2000: 3; see also H. Moore 1994:131).

⁹ In the West, I suggest, a person is only allowed to inhabit one psychological identity at a time, hence the problems in understanding and treating phenomena such as multiple personality disorder (see Littlewood 1996), and 'dual-diagnosis' (e.g. having a learning disability *and* mental health diagnosis, for which service provision has been made only relatively recently).

Such cross-cultural studies tend to concur with the views of Bogdan and Taylor who have argued that the concept of: ‘mental retardation exists in the minds of those who use it as a term to describe the cognitive states of other people ... It is a reification - a socially created category which is assumed to have an existence independent of its creators’ minds’ (1981: 7). Consequently, an important approach to exploring the social and cultural construction of ‘learning disabilities’ is to examine the changing classification and terminology over time. As Bogdan and Taylor assert, ‘To name something is, in a sense, to create it’ (ibid.). As will be shown in Chapter 2, anthropology and the social sciences in general have not always had a benign role to play in the lives of people seen as ‘incompetent’.

Drawing influence from such works on learning disability and personhood, this thesis shows how in Britain (and much of the West), the treatment of people with learning disabilities is largely governed by deeply embedded cultural discourses concerning ‘rationality’, and ‘normality’. It seeks to show how these dominant discourses can perhaps be challenged through participation in aesthetic activity, and to highlight ‘normalising tendencies’ which pervade this society as a whole.

iii) Social Policy and Learning Disability

The examination of social policy and welfare in the West traditionally has been left to sociologists; ‘the label ‘sociologist’ denoting a scientific examination of one’s own society *for its own good* (Jackson 1987:7 cited in Warren 1998:183, original emphasis). This is partly a consequence of anthropology’s links with colonialism, which, as Jackson (1987) has pointed out, has often led to a hostile reception when research is

conducted in the West. This has had the unfortunate implication that ‘an anthropologist is above all the voice of a region rather than of a theory or intellectual innovation’ (Okley 1996:1). According to Warren (1998), the contribution that anthropologists can make to the study of Western society through, for example, the application of participant observation, in-depth qualitative research and longitudinal studies, has only recently been acknowledged, despite the valuable insights the discipline can offer.

The major social policy affecting people with learning disabilities in England today is ‘community care’, which is an issue touched on throughout this thesis. During the 1990s there were a few attempts by anthropologists to tackle this policy¹⁰, which, if seen in ideological terms, presents very interesting issues about how English society cares for the dependent sector of its population.

One of the major questions arising from the study of this policy is ‘what is actually meant by *community*?’ The proposition that: ‘the current clinical notion of the *community* is not just a physically delineated arena in which people live and work, and in which their suffering occurs and is alleviated, but as the virtual location to which suffering and misfortune are now dispersed’ (Littlewood 1999:402), provides a useful starting point. Additionally, it is important to note Davies’s observation that: ‘Care in the community no longer represents an innovation in the delivery of welfare services but has become the orthodoxy in service provision’ (1998a: 120). What ‘care in the

¹⁰ See for example *Anthropology in Action* edition on Community Care and social policy 1992, and Edgar & Russell (eds.) 1998, *The Anthropology of Welfare*.

community' actually means will be explored, predominantly in Chapter 3, breaking it down into its component parts (i.e. 'care' and 'community').

A general consensus exists among politicians, service users and providers that 'community care' is a 'good thing'. However, there have been problems with the policy since its implementation. One which I address in my thesis is the impact of relocation from hospital to *community* on the lives of people with learning disabilities. Research by Emerson and Hatton asserts that: 'There is little evidence to suggest that with community-based services users are developing new competencies, new relationships or extending the extent of their participation in their surrounding community'(1994:44). The investigation of ways of assisting people with learning disabilities to participate in ordinary, non-segregated activities in their local *communities* and to build personal networks which do not rely entirely on special services is considered, therefore, to be of some importance. It will be demonstrated that 'community care' operates at both a theoretical and ideological level, as well as at a material level. At the same time, the concept of 'community arts' is explored, and how this fits in with the locus and practice of 'community care', particularly in relation to a specific group of people who have learning disabilities in south-east London.

iv) Context of the research

The location of the research, in and around London Docklands, has a unique bearing on research findings. This area became a target for government intervention in the form of urban regeneration, orchestrated by the London Docklands Development Corporation (LDDC) in the 1980s. This area had become extremely impoverished with high levels of

unemployment and urban decay. During the 1970s and continuing up until the late 1980s, large numbers of people with learning disabilities who had previously resided in local asylums (predominantly Darent Park and Grove Park Hospitals) were 'resettled' into this area, often without much forethought for their social, cultural or material needs or preferences. At approximately the same time, beginning in the 1970s, arts practitioners and students from Dartington College of Arts (based in Devon) set up projects in south-east London (and Plymouth), influenced by the contemporary vogue for 'community arts' in inner city areas.

As well as addressing the problems of the non-disabled Docklands' population, the artists from Dartington began some work with people who had learning disabilities, many of whom had 'returned' to the area after many years of absence in the asylums. Attempts at 'integration' and 'community participation' were facilitated by the Dartington arts practitioners. This practice needs to be seen against the background of development in the area, where, despite the government's proposed aims to the contrary, LDDC regeneration served to polarise social classes. Luxury apartments were built alongside badly maintained social housing (with the former sometimes being separated from the latter by high security gates), and extremely little interaction occurred between the groups, with many 'locals' resenting being 'priced out' of the area.

Over time, Dartington withdrew its projects, although several practitioners stayed behind in the area. In the late 1980s a new company was set up (New Moves) by a former Dartington practitioner, David Slater, aiming its work specifically at the

marginalised and isolated people with learning disabilities in this area of south-east London. New Moves later changed its name to Entelechy, and it was with this company that I was actively engaged in research in the late 1990s. The evidence collected during fieldwork suggests that the members of Entelechy were committed to social change and improvement in the ‘quality of life’¹¹ for people with whom they were engaged. They set up many unique projects aimed at accessing the creative abilities of a wide spectrum of people with learning disabilities, including the most profoundly disabled, often carrying out experimental forms of ‘the arts’ aimed at facilitating communication. It is this practice, which I have termed ‘cultural intervention’ (borrowing the term from Kershaw 1992), which is the main focus of this thesis, touching as it does on many salient themes connected to ‘learning disability’ such as ‘community care’, choice, control and risk, advocacy¹²; communication (both linguistic, textual, visual, and embodied); medical assumptions about ‘pathology’ and the place of ‘therapy’ and the ‘arts’.

Research was carried out in various venues, including day centres for people with learning disabilities, community centres and a community arts centre. The majority of my time was spent in New Cross, Rotherhithe and Lewisham, although other areas of south-east London were frequently visited. Regeneration by the LDDC brought much investment in terms of businesses and private residences, some of which were built along the former wharves and quays. Infrastructure was improved to an extent, and easier transport links into the centre of London have been built. However, as mentioned

¹¹ This is an ambiguous term, which is subjectively defined. This issue is returned to in Chapter 8.

¹² See Appendix III.

above, the locality had become very polarised socially. Around neighbouring New Cross there was little sign of new investment. The area was in a state of urban decay, with high crime rates and very obvious signs of poverty. This, as I explore in later chapters, was the type of environment which, in the latter decades of the twentieth century, attracted social and cultural intervention by, among others, ‘artists’, seeking funding to create *community arts*. Additionally, as noted previously, this area absorbed the population of two nearby ‘mental handicap’ hospitals as the policy of ‘community care’ came into operation. Most of these people were re-housed in social housing, usually in run-down areas, and were often not particularly welcomed by those already living there. The notion that there was a *community* into which vulnerable people could be moved and be *cared* for seemed particularly inappropriate here, far away as it was from the *gemeinschaft* ideal on which the ideology of ‘community care’ was based.

David Slater’s arts company was based mainly in the boroughs of Lewisham and Southwark, and concentrated most of its work on people with complex needs. The main stated objective was to use arts practice to enable adults with learning disabilities to work with others from their *communities* in new and ‘valued’ ways:

The company works in partnership with health providers, local authority directorates, voluntary sector organisations, informal networks of people, arts and social action funders and educational institutions. Many members of the company have spent the greater part of their lives in long-stay hospitals. An intensive programme of arts and cultural activities aims to integrate members with their non-disabled peers from local communities.

(Extract from Entelechy document)

For the majority of my research, Entelechy’s offices were based within a day centre for people with learning disabilities. An arts organisation (voluntary sector) based within a social services premises (statutory sector) was an unusual juxtaposition, and brought

about many chance meetings and unsolicited interruptions. This location was deliberate on the part of Entelechy, as it gave access to its target population (people with learning disabilities) at a 'grass roots' level on a daily basis, in an environment with which they were familiar. Also, it put Entelechy in a position in which opportunities could arise where the dominant ways of treating people with learning disabilities (i.e. social services and medical models of disability) could be questioned and challenged, in line with Kershaw who argues that:

The politics of post-modern performance, if it aims in any way to be oppositional, must be one of resistance from within the dominant. To be most effective, such politics would need to subvert, as it were, the building blocks of the dominant, to undermine the main strategies that it uses to maintain itself. The key political problem then becomes: how can performance, in being always already implicated in the dominant, avoid replicating the values of the dominant.
B.Kershaw 1996:141

Through various workshops, groups and performances, Entelechy engaged and worked with many people who had learning disabilities from within the local population. Some relationships had been built up over a number of years, while others were much more recent.

Entelechy was funded from a number of sources, including the Department of Health and grants from the boroughs of Lewisham and Southwark. Consequently it often had to justify its work using its funders' rhetoric, which usually veered towards a rehabilitative model of the disabled person (i.e. through involvement with the organisation they will somehow 'improve' or get 'better'). This, in turn, affected the autonomy of Entelechy, and it was through 'ideological work' that Entelechy attempted to reassert this autonomy. For example, in the various meetings that were held by the company, what was and was not 'Entelechy' was debated, resulting in more than just a token inclusion of learning disabled people on advisory panels, and profoundly disabled

people being employed as ‘trainers’¹³. A few months before my fieldwork ended, Entelechy moved out of the day centre into a nearby arts centre, and was consequently removed from the direct culture of social services.

v) Researching with People who have Learning Disabilities

Disabled people have come to see research as a violation of their experiences, as irrelevant to their needs and as failing to improve their material circumstances and quality of life.

Oliver 1992: 106

Spradley’s (1980) argument (mentioned earlier) that ‘good’ informants should be thoroughly ‘enculturised’ could perhaps be seen as presenting social anthropologists with particular problems when conducting research with people who have learning disabilities. Creating an ethnographic account based on the experiences of a group of people who are seen by many to be ‘outside’ culture, could appear to be a very difficult task. However, it is precisely because this group is seen as ‘outside’ of culture, that they present a very interesting and worthwhile subject of study. Is the social exclusion of these people so extreme in Western culture that they are viewed by many as non-human? People with learning disabilities, especially those labelled ‘profoundly disabled’, are often seen, both by many academics and the culture in which they are (however tentatively) embedded, as being on the margins of existence. As dependent adults, they present cultural and social anomalies, particularly those who have been sequestered for large portions of their lives, separated from kinship networks and prevented from reproducing, but who have now been perfunctorily returned to a social existence in *the community*. How then, could their involvement in ‘community arts’ affect or improve their situation? In this research I examine one such attempt by a group of artists,

¹³ See Chapter 5.

Entelechy, who communicated with and helped to express creatively the experiences of such people.

This research focuses on the experiences of a specific group of people with learning disabilities, many of whom were not able to give what conventionally would be understood to be 'informed consent' to participation in this study. Swain et al (1998) suggest that the principle of 'informed consent' is ostensibly straightforward:

The participants' unquestionable right to make a voluntary decision of whether or not to participate in the research. It requires the decision to be 'informed' by an understanding of what the research entails, and it requires the capacity to 'consent'. Informed consent is, arguably, a safeguard which protects the rights of participants and fulfils the responsibilities of researchers .

Swain et al 1998: 28

This issue evidently raises many ethical concerns. Research was not carried out in a medical setting, so no 'board of ethics' was consulted. Access was approved by the company director, David Slater, and also by Entelechy's facilitators¹⁴. The way in which I came into contact with my informants was through their involvement with Entelechy, whose non-disabled facilitators were fully aware of my research project. Sessional artists, care workers and various other individuals involved in Entelechy's projects (who did not have learning disabilities) were made aware of my role as an anthropologist carrying out research.

After consultation with my supervisor and colleagues, I decided to use pseudonyms for my informants who had learning disabilities, largely due to the ethics around the issue of 'informed consent'. I tried to explain to all my informants who had learning disabilities

¹⁴ I will refer to Entelechy members who did not have learning disabilities (or physical disabilities) as 'facilitators'. In calling themselves 'facilitators' there was a conscious desire to promote the idea that

my intentions, which were to gain an understanding of their experiences as a member of the arts company, contextualising this with any other information about their lives that they wished to provide. This worked well in some instances, in particular, as illustrated in Chapter 7. However, in many other instances, terms such as ‘anthropologist’ or ‘research’ did not appear to hold much meaning for my informants, especially in situations where verbal dialogue could not be entered into. Although I could sign using the Makaton augmentative communication system¹⁵, many of my informants were only able to understand very basic words, and a response of ‘yes’ to a question could not be taken as a clear indication of ‘informed consent’. In such cases, carers and Entelechy’s facilitators assumed the role of ‘consent givers’, and as trust was built up fairly rapidly between myself and the company, I was never denied access to information relevant to my research.

I agree with the guidelines of Swain et al (1998) who suggest that with learning disabled informants, including those individuals who appear very competent, the direction of open-ended questioning and interviews cannot be predicted. They assert that ‘informed consent is not simply contracted at the outset, but is a continuous process to be re-affirmed as the research progresses.’ (Swain et al 1998: 28). In an article on collaborative research with people with learning disabilities (who appeared to be quite competent verbally), the practice of continuous meetings between research partners to establish ‘ongoing consent’ is suggested, as this ‘offered both the informant and the inquirer the opportunity to not only consent to, but also contribute to the topics for discussion’ (Knox et al 2000:57). This method was also employed by Entelechy in

they were not specifically directing the action, but that action could be spontaneously directed by any

all of their projects, specifically the life-histories project described in chapter 7. However, with people who could not communicate very well, this process was very difficult to apply, and carers and family members were consulted to act on their behalf.

The high level of various forms of abuse suffered during the lives of the learning disabled population in general¹⁶ inevitably was reflected in many of the stories and actions related and performed during the course of Entelechy's workshops, performances and projects with which I was involved. I regularly consulted with the non-disabled members of Entelechy if I felt overtly concerned about an individual, and asked how they would wish me to respond to further incidents or disclosures in workshop or performance situations. Entelechy was in constant dialogue with the learning disabled people's support networks (predominantly centring around day centres, residential care homes and hostels), and there were mechanisms in place where any concerns could be raised. I was guided by the ethical codes of Entelechy¹⁷, which were based around mutual respect. Entelechy's 'action research' project, 'Rediscovering Our Histories', examined in Chapter 7, raised important issues similar to those pointed out by Fox:

Researchers often seem to ignore the fact that active participation in a research project, even on a purely verbal level, may arouse feelings, stir memories, or force perception which otherwise may not have occurred.

Fox 1976:63

member of the group, regardless of ability.

¹⁵ See Appendix IV.

¹⁶ See the following for research examining the abuse of people who have learning disabilities: Sobsey 1994; Millard 1994; Sinason 1994; McCarthy & Thompson 1995.

¹⁷ These were implied rather than explicit although guidelines for volunteers and those participating in the Rediscovering Our Histories Project and other specific projects were drawn up.

To research and report experiences of abuse, as Swain et al (1998) have pointed out, developing earlier ideas of Booth and Booth (1994), can, in turn, be abusive:

The essentially political act of research can exploit vulnerable and powerless groups within society, further their disempowerment and contribute to their oppression. This challenge is particularly acute when ... the subjects of research have learning difficulties and research is concerned with issues which might be deemed intimate and personal. People with learning difficulties can be particularly vulnerable to manipulation and exploitation by researchers.

Swain et al. 1998: 22

Both Entelechy and myself were very aware of this, and all measures possible (e.g. regular consultation and supervision) were taken to prevent distress occurring. I have tried to be as aware of and alert to these ethical issues as possible, providing sensitive background information only where judged to be necessary and relevant. Further issues concerned with conducting research with this group are discussed below, in the section on methods.

I have worked with many people labelled as having learning disabilities, in several different capacities¹⁸, and hope that I have built up some understanding of and ability to relate to their experiences. This research could, in part, be interpreted as belonging to the 'excluded voice thesis', so termed by Booth, which 'postulates that narrative methods provide access to the perspectives and experiences of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse' (1996:237). However, through researching mediums other than the purely oral and textual, I aim to move beyond this to a more collaborative approach.

¹⁸ In addition to carrying out anthropological based research with this population (in both Scotland and England), I have, in the past, worked with learning disabled children and teenagers as a care worker; play worker, and as a learning support assistant.

In much of the ethnography, linear narrative threads become largely unimportant (except where explicitly requested by the subjects themselves). Kaleidoscopic and shifting realities appear to take precedence, challenging aesthetics and conventional paradigms of relating informants' experience. Obviously my own interpretations of experiences such as dancing with people with profound and multiple disabilities, who cannot communicate through normative cultural modes, is highly subjective. By attempting to allow the informants to guide the structure of the relating of their experiences, this overtly challenges cultural assumptions about such people, as Booth describes:

People with learning difficulties have mostly been treated as objects of study rather than credited with any integrity as people. They have generally been seen as problems for other people rather than as individuals with lives of their own. The primary focus has been on their deficiencies rather than their capacities (Mount & Zwernik 1988). Such attitudes and assumptions have encouraged the view that the basic tenets of qualitative research do not hold up well in the study of people with learning disabilities.

Booth 1996: 238

vi) Access and Methods

Initially I approached Entelechy in December 1996, and negotiated research access with them from January 1997. I worked in the role of a volunteer/researcher on a part-time basis between January and August 1997, and as a full-time volunteer/researcher between September 1997 and December 1998. I also attended additional projects in Spring 1999. I established a good working relationship with the company, and was invited to attend planning and management meetings as a participant observer, making transcripts of meetings. I conducted informal and some semi-structured interviews with the disabled and non-disabled members of the performance company, including local

volunteers. I took photographs, with permission¹⁹, of most workshops and performances. I became thoroughly incorporated in the company and was often asked to document events for the company's own archives. Some photographs which I had taken were used to illustrate the company's publicity material, and I was involved in making a training video.

Although I came into contact with, and interacted with, some of the paid carers and support staff who worked with the people with learning disabilities within my research group (and very occasionally came into contact with family members²⁰), these people were not the focus of my study, and usually will be mentioned only in direct connection with Entelechy's projects and workshops.

My relationship with my informants was complex, as I was neither an artist nor a social services employee, but a researcher from another part of London who suddenly appeared in their lives. I worked as a volunteer in most workshops, often simultaneously assisting others and creating my own paintings and sculptures side by side; sometimes I was a 'performer' alongside other members of Entelechy. Occasionally I physically cared for people while they were having epileptic fits or needed help in using the toilets. I considered myself to be foremost an anthropologist, but I made the decision early on in my fieldwork to 'tread lightly' as a researcher, relying predominantly on participant observation, and keeping formal interviews to a minimum, as I wished to disrupt their activities as little as possible. Most of my

¹⁹ It was not possible to ask directly some of the more profoundly disabled people if I could take their photographs, and permission was asked instead from carers.

interviews were extremely informal and took the form of extended conversations, or dialogues during meetings and ‘happenings’.

I tried to explain to people with learning disabilities as well as I possibly could who I was and what I was doing, but this was difficult or impossible in many cases. I gradually became identified by many of the people with learning disabilities as just another member of Entelechy, who wasn’t particularly good at dance and drama, but would join in anything in a non-authoritative way, if they so wished. I came to understand that I had become a stable reference point for some of the people with learning disabilities with whom I had regular weekly contact. Paid carers frequently changed²¹, and as I was present for well over a year, this seemed to have a positive affect on their relationships with me.

Several studies by social scientists such as Booth (1996); Atkinson and Williams (1990), and Atkinson, Jackson and Walmsley (1997) have shown that it is possible to use narrative methods with people who have learning disabilities. However, especially with people who did not use conventional or recognisable language, it was much more

²⁰ By far the majority of the people with learning disabilities with whom I conducted research did not live in family homes, but in group homes and hostels run by voluntary and statutory services.

²¹ Largely due to low pay and difficult working conditions.

appropriate to use participant observation: and this was the main method I used throughout the fieldwork, making detailed fieldnotes of the various workshops and projects²². Wilkinson, a psychologist, terms this kind of research with people who have learning difficulties as 'being there'. Describing her experience researching in a community service for people with severe learning difficulties, she comments:

The immediacy of events and people, who featured regularly within the experience of (service) users, acted as a memory-aid to prompt the answers to the questions asked by the researcher. With the man who did not speak or sign at all, the change in facial expressions and body posture when exposed to different people and places offered a great deal of insight into how he was feeling. These experiences were noted in diaries that were used to document each person's experiences and reactions.

J. Wilkinson 1989:57

Flynn (1986) has devised guidelines for interviewing people with learning disabilities, offering strategies for overcoming potential problems such as a tendency among people with learning disabilities to conform to other people's expectations during an interview.

However, as Knox et al point out:

It could be considered that the challenges of acquiescence and social desirability outlined by Bilken & Moseley (1988), Heal & Sigelman (1990) and Wyngaarden (1981), amongst others, as issues of concern in interviewing people with an intellectual disability, are simply indicative of a reluctance on the part of the informant to allow the inquirer access to his or her world.

Knox et al. 2000:56

One way of overcoming this, suggested by Fido and Potts (1997) is to use open-ended questions and re-interview people several times, enabling them to feel more at ease to disclose further information. Re-interviewing, they suggest, also allows points raised to be followed up and additional information to be obtained. This, however, raises questions about privacy, and a continual 'wearing down' by an interviewer may be

²² The use of participant observation and 'life history' approaches have proved much more successful with this population than survey techniques, which, as Sigelman et al (1981) have pointed out, are often not very informative. This may be due to a tendency among people with learning disabilities to be acquiescent to interviewers (see also Angrosino 1989, and Bercovici 1981). .

considered unethical. I did not pursue single lines of enquiry with my informants, and did not enter into any topics with which they appeared to be uncomfortable. As far as possible, I let them guide our interactions. As I saw the same people on a weekly basis, it was possible to ask questions (in a reciprocal way) over an extended period, with my informants becoming more open as trust was built up over time.

Atkinson and Williams (1990) have also explored different ways of conducting research with people who have learning disabilities. They have looked at enabling them to 'convey their subjective experience; through sensitive interviewing ... or through 'being there' and experiencing the rhythm and content of people's days at first hand' (1990:237). As mentioned above, I examine the notion of 'embodied', non-verbal communication, in particular during dance and movement workshops with the profoundly disabled. Fido and Potts (1997) suggest that one way of accessing the views of people with severe speech difficulties is to use their friends, who have known them for a long time, as interpreters. However, this method may bring up problems such as the accuracy of the interpretation, and issues of confidentiality. Very little work has been done, however, on researching techniques for interviewing or recording the experiences of people with profound disabilities who cannot communicate verbally. I have attempted to develop such techniques, often learning from the arts facilitators, using sensory and non-verbal modes of communication, for example, during the dance workshops. Additionally, as part of the 'Rediscovering Our Histories' project, I have sought to document the compilation of personal biographies using sensory devices, rather than just text, acknowledging the non-sequential and kaleidoscopic results as as valid and informative as any conventional textual account.

The research, therefore, necessitated the utilisation of a combination of methodologies. Historical and theoretical approaches to the subject are combined with ‘grass roots’ data. A few of my learning disabled informants were competent in articulately addressing issues which affected their lives, and were confident in speaking publicly. I also attended several Open University conferences held in Milton Keynes, where several people with learning disabilities (from across Britain) gave short lectures. However, the majority of my learning disabled informants had great difficulty getting themselves heard in their daily lives, let alone in a public forum, partly due to the dominance of certain perceptual modes of interpreting lived experience (i.e. through visual rather than tactile media). Structures of power shaping disabled people’s lives are acknowledged in my approach. Additionally, in certain cases I have attempted an ‘embodied’ approach to the material, crediting the very real bodily challenges which many of my informants experience. As Crossley (1996a) suggests, we do not have to choose between Foucault’s ‘inscribed body’, and Merleau Ponty’s ‘lived body’, ‘these conceptions are not only commensurable and compatible, they are mutually informing and complementary’ (1996a:99).

vii)Chapter Outlines

Chapters 2 and 3 are largely theoretical in content, providing an historical and theoretical background to contextualise the fieldwork; and examining the concepts of *community*, and ‘the arts’. Chapter 4 looks at the links between ‘art’ and ‘life’, drawing on anthropology, disability and performance theory, relating this to specific projects carried out by Entelechy, including one involving young people with learning disabilities

and ‘transitions’. The ideas of ‘intent’ and ‘choice’ in performance are examined, as is performance efficacy in creative activity involving people with learning disabilities and/or profound and multiple disabilities.

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The later chapters explore several other Entelechy workshops and projects, integrating theory and ethnography. Chapters 5 and 6 are focused on Entelechy’s ‘Combined Arts Programme’, with Chapter 5 dealing with issues specifically relating to people with profound and multiple disabilities and their involvement in workshops and performances. The use of the ‘arts’ as a communication channel is explored, in particular ‘embodied communication’. Issues around representation, subjectivity and corporeality are addressed. This is based around fieldwork in two on-going workshops, performance projects, ‘happenings’ and training events.

Chapter 6 looks at issues of protest and resistance by people with learning disabilities, and is based on data gathered from participant observation in a weekly drama and movement workshop held in a day centre, catering for people with ‘low support needs’, that is, people with learning disabilities who were viewed as fairly competent in most areas of their lives. Behaviour labelled as ‘pathological’ by the medical profession is examined and interpreted more in social and cultural terms (i.e. as a powerful form of protest).

Chapter 7 examines Entelechy’s project, ‘Rediscovering Our Histories’, funded by the Department of Health. This was a three year development programme exploring methods and strategies that could be used by former residents of long-stay hospitals to

re-establish contact with lost family members and friends. It also supported individuals in creating personal biographies, and sharing life experiences with their non-disabled peers. Methods used to relate and record memories and experiences included theatre, video, photography, music and sensory devices. I examine the project and its effects on its participants. The final chapter, Chapter 8, draws conclusions from the data and literature presented, focusing on the use of the arts as a 'meeting ground' for people of widely differing abilities.

A core theme linking all of the chapters is the idea of 'transformation'. This refers particularly to the creative and performative activities with which Entelechy and a large group of people who have learning disabilities are engaged. This 'cultural intervention' in their lives needs to be understood alongside deeply entrenched medical and psychological discourses concerned with disability, such as, that activities should be 'rehabilitative' and/or 'therapeutic'. This is indicative of the metanarrative that interactions between disabled people and non-disabled professionals (doctors, therapists and carers), should be somehow 'transformative'. The belief is that even the chronically disabled can be 'improved', or 'normalised'. However, the movement referred to as 'disability arts' today runs very much in opposition to these discourses. 'Transformation' as a process, however, needs to be separated out from these medical and social discourses. 'Performance', whether or not involving disabled people, is inherently 'transformative', and engagement in such activities can take on a political and radical dimension. The 'performative self' (Goffman 1990) in an aestheticized (Hughes 2000) and dramatized (R. Williams 1983) society is explored in chapters 2, 3 and 4, setting the scene for an exploration of cultural intervention in the lives of people who

have learning disabilities. In order to understand the current situation of people with learning disabilities in Britain, it is necessary to examine how they are understood as persons (or non-persons) in the West, which results from a combination of specific historical, philosophical and cultural discourses, and this will be addressed in the following chapter.

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Chapter Two

The Normal and The Abnormal: Alterity and the Formation of The 'Incompetent' in Western Discourse

If the 'right to normality' is not to become a whole series of pressures on mentally handicapped people to change and conform to other people's standards, then this right must include both the right and the means to question that normality, and to live a different life, one that is an enrichment rather than a deprivation of 'normality'.

Ryan & Thomas 1987:134

i) Introduction

The question of 'what does it mean to be human?' has been explored endlessly throughout history. Many English terms exist to describe human beings, such as 'person', 'self', 'individual', but they do not necessarily refer to the same thing. Metaphysical, psychological and anthropological views of humanity are rarely congruent. A large literature exists which addresses this problem, both from other social science disciplines (e.g. Foucault 1987; Taylor 1989; Rose 1990, 1996), and from within anthropology (e.g. Mauss 1985; Dumont 1985; Mead 1934; La Fontaine 1985, Strathern 1987, 1990, 1992a, 1992b; Lawton 2000). What is salient here is the question of how those humans deemed as 'incompetent' are conceptualised in terms of 'persons', 'selves' or 'individuals'.

A cross-cultural approach to learning disability was touched upon briefly in Chapter 1, which showed that who becomes categorised as 'incompetent' is quite variable, both culturally and historically. However, it was suggested that some competencies

necessary to demonstrate what it means to be human were seen to be fairly universal, such as language usage and comprehension, 'reflexivity', participation in the local lifeworld, and the 'individual capacity to construct personally satisfying identities' (Jenkins 1998:227)²³. In modern Western society, academics such as Giddens (1991) have argued that a 'person' is composed of a 'self' and an 'identity', which are separate but interdependent. This idea is also embedded in a wide body of work, summarised by Lawton in the following terms:

The self is one's inner subjective being; it is an essence which, in this particular cultural and historical context, is interior to the subject/person (Taylor 1985). Identity on the other hand is externally dictated; it is derived from the cultural meanings and community memberships that others confer upon a societal member. In other words, identities develop in both stable roles and in the emergent situations of social interaction (Goffman 1959) ... In practice, however, one's self and one's identity are often fundamentally entwined ...

J. Lawton 2000: 5

As will be shown in this chapter, throughout Western history, the humanity of people with learning disabilities has been the subject of continuous debate, that is, their 'personhood' is in question. They have often been compared to animals or other entities beyond the human realm; in other words, they are outside of 'culture'. In the case of people with severe learning disabilities, as the anthropologist Edgerton has pointed out, many are 'unable to comprehend or follow most of their culture's rules, from implicit conventions to moral and supernatural rules. As a result, these persons require - and sometimes receive - almost total exemption from responsibility' (Edgerton 1985:81-2). As a consequence of how 'persons' and 'selves' are perceived in the West, i.e. as autonomous, bounded 'individuals', those who are deemed incapable or unable to fulfil these criteria have their personhood in question. Their existence as a category,

²³ Post-modernist anthropological critiques of what an 'individual' or 'person' is using cross-cultural ethnographic data may contest this, e.g. Strathern's work in Papua New Guinea, 1990. However, for the purposes of this thesis, it will be assumed that Jenkins' proposition holds true.

however, becomes necessary in order to define what a 'person' is *not*. Levi-Strauss' idea that dualist thought is innate to all cultures has been shown by deconstructionists to be itself a cultural construction. However, this does not mean that it is not a very powerful mechanism continuing to operate in contemporary society. What is of interest here is the development of a specific self/other dualism, that of the 'normal' and the 'abnormal' which has been extremely influential in the development of the alterity of the incompetent in Western society. As recent works by anthropologists have shown (e.g. Strathern 1992a, 1992b; Lawton 2000), the ideal of an 'autonomous, unique, individual' is far from a reality. Most people construct themselves through relationships. As Strathern points out in relation to English kinship, 'Individuality would thus be both a fact of and "after" kinship' (1992b:15). Lawton's study of the processes of death and dying in an English hospice draws a similar conclusion:

Whilst members of contemporary Western societies often conceive of themselves as unique and autonomous entities, such a notion of person and self is often dependent upon, and realised through, interpersonal relationships which are themselves based upon a certain level of mutual autonomy.

J. Lawton 2000:5

This inevitably impacts on how people with learning disabilities are seen. Their need for support from others both diminishes their personhood (they are in the anomalous category of 'dependent adults'), while at the same time being positioned within a social network which, often consisting of kin and non-kin, supports their claim to personhood (although the paucity of actual social interactions frequently negates this). This fragile notion of 'the self' is further complicated through the transitions incurred by many people during the processes of institutionalisation, and subsequent return to *the community*, which are explored further in Chapter 7. Anthropologists such as Bloch (1988); Morris (1991), and Moore (1994) have tried to show the complexity of

contemporary concepts of 'personhood' and 'self' in Western society. As Lawton has shown, there is 'no simple distinction between "high theory" on the one hand and "folk" understandings on the other' (2000:7), rather people combine aspects of both. What does emerge, however, is the continued 'alterity' of disabled people, which appears to be largely premised on the body, which in turn is related to pervasive ideas about the aesthetic integrity of the 'self'. This, as will be shown below, is as applicable to people with learning disabilities as it is to people who are physically impaired.

'Disability' as a subject area in the study of alterity has (relatively recently) been subsumed within anthropology's agenda of the examination of 'otherness'. According to Hughes, 'Modernity claims the overcoming (*Aufhebung*) of alterity as a master narrative in its historical project of emancipation' (2000:557). This resonates with the social scientist, Stiker's (1982) claim that a 'denial of difference' characterises the present attitude to disability, and, I suggest, this attitude is reflected in social policies such as *normalisation*. Social care policy for people with learning disabilities in much of the West is influenced by the ideology of *normalisation*, developed in the 1970s and widely disseminated by the American theorist, Wolfensberger. Put very crudely, the policy advocates that people with learning disabilities should conform to the most conservative social norms in order to be socially accepted. The stigma inherent in having a learning disability, according to this theory, will then be decreased. *Normalisation* has both proponents and critics within this area of work, but if its guidelines were strictly adhered to, much of Entelechy's work would not take place, as it could be seen as not being 'age-appropriate'. The reason for this is because some of the activities engaged in do not reflect those in which a 'normal' adult would

participate. It is suggested that the blanket application of *normalisation* creates a 'pseudo-reality', in which gender stereotypes and behavioural norms of an imagined ultra-conservative society are presented 'as if', in reality, all of society naturally conforms to them. Performance art/theatre is an arena in which such 'norms' or 'pseudo-reality' are frequently challenged. As will be shown in subsequent chapters, the work of Entelechy goes some way towards doing this. *Normalisation*, which sits uncomfortably between existing as a social policy and an ideology, will be examined later in this chapter.

Stiker has studied 'the emergence of rehabilitation as technical and social adjustment of the individual' (Ingstad & Reynolds Whyte 1995: 21) in Western civilisation. The 'annihilation of difference', however, is a contradictory process in Western modernity, as Hughes points out:

It implies progress towards purity, perfection, truth, reason - all the ideal high watermarks of the modern attitude. On the other hand - despite its utopianism and search for absolutes or perhaps because of them - modernity is marked by the constitution of alterity, by ubiquitous and marginalising social processes of 'othering' in which subjects are constructed as either one or the other, woman or man, black or white, disabled or non-disabled, and so on.
B.Hughes 2000:557

The critique of 'disability' as a social and cultural phenomenon, rather than as a pathological condition (i.e. 'social' versus 'medical' models of disability) has been fairly slow to develop. An anthropology of 'disability' was advanced by several publications in the 1990s, one of the most influential being Ingstad and Reynolds Whyte's (1995) *Disability and Culture*. The contributors looked at how impairments relate to personhood and to culturally defined differences among persons. They illustrate how, cross-culturally, notions of disability/impairment are extremely complex and varied; and

that it cannot be taken for granted that a notion of 'disability' exists within a society. They argue instead for a notion of 'difference' rather than 'disability'. Stiker's (1982) ideas are drawn upon, taking an historical view of disability, noting a change from 'charitable' to 'medical' models. This has been accompanied, Stiker suggests, by a move from seeing people with impairments as fundamentally 'different', to being fundamentally 'similar'. This change to a 'denial of difference' has created enormous tensions, as, he argues, 'normality' has been created in a context of difference, co-existing with deeply culturally embedded notions of teratology. Movements such as *normalisation* seek, Stiker suggests, to negate disability through integration, and 'melt the abnormal in established and recognised normality by social consensus' (1982:149). This is partly true, but as I argue below, *normalisation* is a fairly complex way of *maintaining* abnormality. It is important to marry historical discourse analyses, such as Stiker's (1982), with those of 'lived experience', i.e. the narratives of people with disabilities (however they are culturally conceived). Concurring with Reynolds Whyte (1995), I suggest that this is the way forward for an anthropology of disability. In this chapter I take a theoretical look at the various cultural and historical discourses defining 'normality' and 'rationality' in the West which impact on current conceptions and policies concerning people with learning disabilities. Ideas around the aesthetic representation of disability and the disabled body are also explored, thus providing a background to understanding the data and arguments in subsequent chapters.

ii) The Normal and the Abnormal

Accepting the Foucauldian proposition that the study of 'abnormality' is one of the major ways through which relations of power are established in society, it is useful

briefly to look at the institutions and individuals who were (and still are) responsible for defining 'normality' in relation to the classification of people with learning disabilities. Historically, in the West, religion has had a major impact on the treatment of those deemed 'incompetent'. This has been explored by the historian Scheerenberger (1983), who argues that two of the most influential ways of conceptualising learning disability have Judeo-Christian origins; firstly that they are 'the innocent children of God'; and secondly the notion of 'original sin' which contradicted the notion of innocence: 'These two contrasting beliefs, which provoke an uneasy mixture of pity and fear, provide an important backdrop to the history of services for people with learning disabilities and help us to understand public attitudes concerning these issues' (Jahoda 1995:206). A common diagnosis for people afflicted with disease and/or disability up until the Middle Ages in Europe, was that the sufferer was possessed by the devil. Alternatively, Jenkins (1993) suggests that a child born with learning disabilities may have been viewed as a 'changeling', the real child having been stolen by fairies or trolls: 'one recommended treatment for a changeling was to drive the impostor out using fire, another was exposure to the elements. The abandonment of the incompetent to their fate can be attested to in the nineteenth-century British Isles as well as the twentieth-century arctic' (Jenkins 1993:18). As Ryan and Thomas have pointed out, 'Before the eighteenth century discussions of idiocy are scattered and fragmentary; those that do remain show clearly a preoccupation with the human status of idiots and with their origins' (1987:86). One of the few existing works mentioning 'fools' is by the 16th century Swiss physician Paracelus, who argued that 'fools' are closer to God. As will be further discussed in chapter 6, the belief that 'idiots do not suffer from as many worldly corruptions as others and are nearer to some truer or more basic conception of human

nature persists into the present' (Ryan & Thomas 1987: 87). The writer Daniel Defoe called for some kind of public provision for 'idiots', towards the end of the 17th century, taking the form of a 'public fool house', 'to be paid for by a tax on learning, levied on the authors of books, on the grounds of a kind of natural justice' (Ryan & Thomas 1987:91). However this did not come to fruition. Defoe was also interested in how 'fools' could be fitted into humanity:

'Perhaps,' he wrote, 'they are a particular Rent-Charge on the Great Family of Mankind left by the Maker of us all - like a younger brother, who tho' the Estate be given from him, yet his Father expected the Heir should take some care of him.' Care should be taken of fools, said Defoe, as a tribute to God's bounty to mankind, a tribute to be paid to all those who lacked this bounty. Defoe also likened fools to animals, for the apparent 'deadness of their souls'.
Ryan & Thomas 1987:91

Other powerful discourses, aside from the religious preoccupation with 'souls', converged in the Enlightenment. These were medical and other 'scientific' academic disciplines concerned with the definition of 'abnormality', 'pathology' and 'alterity', and the measurement and categorisation of human beings (all of which had consequences for the definition of what is now known as 'learning disabilities'). The work of the philosophers, Descartes and Locke, were also (and still are) very influential in outlining what it meant to be 'a person' in terms of 'rationality'. In creating a model of rationality, however, the 'irrational', 'mad' or 'incompetent' are also defined. 'Madness and idiocy' have been, and often still are, perceived as a dyad in Western social and cultural discourse due to the belief that both conditions are rooted in an entity called 'the mind', and consequently affect behaviour. Goodey has traced this dyad back to the remark by the 17th century philosopher, John Locke, that:

Madness is a mis-match of ideas to the external realities that should correspond to them, whereas idiocy is absence of ideas. The account of madness has long been superseded and contextualised. 'Mental handicap' or 'retardation', to use the clinical terminology, as absence of the mental, remains taken for granted. This historiographical situation reflects exactly Locke's hierarchical classification of madness as human and idiocy as non-human ...
C.F.Goodey 1996:93

Similarly in medical anthropology, much has been written on the 'mentally ill', but until fairly recently, very little on learning disabilities. This is a serious omission, and is perhaps the result of a belief that 'everyone just knows what an idiot or mentally handicapped person is, and that it is some unfortunate creature with a deficit in something called intelligence' (ibid.), existing as a trans-historical and trans-cultural reality. Recent publications by anthropologists (e.g. Jenkins ed.1998) and historians (e.g. Wright & Digby eds. 1996) have shown that this is evidently not the case. However, the idea that people with learning disabilities are somehow on the margins of existence, 'non-persons' with little or no agency, persists in Western culture. This is due to a complex of ideas around what it means to be a person in Western society.

In Cartesian terms a person consists of a pure and rational mind (the intellect); a subjective, emotional mind (the will); and an instinctual, but inalienable, body. People with learning disabilities are seen as non-rational, in that their intellect is impaired. This means the person is devalued and incomplete, with the will and the body largely governing behaviour, which has led to their sexuality and 'challenging behaviour'²⁴ being heavily controlled and policed, both today and in recent centuries.

²⁴ The current term used in services to describe 'socially unacceptable' or deviant behaviour, such as violence, self-harm, and public masturbation; a concept which will be returned to later in this thesis.

The (modern) rhetoric of individualism implies that an individual's body is inalienable, but if the 'individual' is assumed not to possess rationality, they are therefore not in possession ('control') of their bodies. Bodily acts and functions have to be regulated by an outside agency, further reinforcing their devalued and dependent status. When religious and 'scientific' discourses were combined, they produced a popular notion of the 'idiot' as both soulless and animal-like in nature, a view which pervaded throughout the nineteenth century (and still has repercussions today). In the late 18th and early nineteenth centuries educationalists such as Itard and Seguin argued that 'idiots' could be 'improved' through education, advocating their 'moral treatment'. However, their humanity continued to be debated. The recurrent historical theme, therefore, is whether or not to attribute humanity to people deemed as 'idiots'. Tools for measuring 'difference' between humans began to be developed in order to answer this question.

Davis (1995), a theorist in both English literature and disability studies, has tried to establish why the concept of 'norm' or 'average' entered into European discourse in the early nineteenth century. He suggests that it had a lot to do with the expanding science of statistics and its application to public health, linking the body to industry: 'The leading members of the first British statistical societies formed in the 1830s and 1840s were industrialists or had close ties to industry' (Davis 1995:26). Davis's research thus supports some of the claims made by historical materialists such as Finkelstein (1980) and Scull (1977, 1979) who have argued that the growth of heavy industry was a major factor leading to the segregation of those unable to 'produce' in the way demanded of them, such as the very old, the very young and people with disabilities.

One of the most important figures in creating ‘a generalised notion of the norm’ (Davis 1995:26) was the French statistician Adolphe Quetelet (1796-1847). Using the distribution of weight and height in a given population, he formulated the notion of ‘*l’homme moyen*’, who was both a ‘physically average and a morally average construct’ (ibid.). Davis suggests that this notion gave credence to middle-class claims of hegemony, with middle-class life representing ‘the norm’, accompanied by the idea that ‘the norm’ was some kind of ‘ideal’: ‘Quetelet foresaw a kind of Utopia in the norm associated with progress, just as Marx foresaw a Utopia of the norm in so far as wealth and production is concerned’ (ibid.:28).

Both Davis (1995) and Jahoda (1995) have noted that the concern with ‘the norm’, which in turn was linked to notions of ‘morality’ in the late 18th and early nineteenth centuries, led to a move in interest ‘away from the protection of imbeciles and idiots towards the protection of society from such individuals’ (Jahoda 1995:207). This is a similar situation to that which has occurred in contemporary Britain, as will be discussed later in relation to the social policy of Community Care. This would seem to suggest that morals, rationality and physiology are inextricably linked in the Western consciousness. This harks back to Cartesianism and earlier Judeo-Christian ideas, and is reflected in debates concerning evolutionism, ‘development’, ‘race’, and gender²⁵.

One of the most important influences was the emergence in the late 18th century of the ‘social sciences’ in Europe, at about the same time as the ideology of the ‘nation state’,

²⁵ An enormous body of literature exists both within anthropology and in other disciplines on these issues, but it is beyond the scope of this thesis to enter into them in any detail here.



and European colonial expansion (S.MacDonald 1993). The 18th century trend towards 'Romanticism' caused speculations as to the 'nature of society' and the 'nature of social development', e.g. Rousseau's notion of the 'noble savage' (1791). The idea of a progressive advance of social forms became widespread in the Enlightenment²⁶. In the Victorian era, the relationship between 'biology' or 'nature' and 'culture' or 'social forms' was further complicated by the publication of Darwin's theories. Stocking argues that Darwin's published work 'lent itself to "social Darwinist" interpretation, just as his personal opinions tended in the same direction', (1987:145). However, Stocking also notes that Galton's work, from which the eugenics movement grew, which is often labelled as 'social Darwinist', was a later development. He suggests that eugenics was:

The product of a period when traditional liberalism, threatened by forces of democracy and collectivism at home, and by those of nationalism and militarism abroad, was no longer the optimistic creed it had once been. Rather than a positive application of the principles of natural selection to the interpretation of social phenomena, eugenics was an attempt to compensate for the failings of natural selection to operate under the social conditions of advanced civilisation.
Stocking 1987: 145²⁷

Phenotypic variations, often seen as the cause of cultural diversity, were charted by white male anthropologists and biologists on the basis of objectifying, measuring and classifying the bodies of indigenous people in Africa, Asia and America, encountered on various 'scientific' expeditions (c.f. Terry and Urla 1995). The 'exotic' other of anthropology and the 'pathological' other of medicine, combined in the scientific imagination. The wild and uncharted needed to be measured and tamed and specimens

²⁶ For example, Montesquieu (1748) proposed an evolutionary scheme consisting of three stages: hunting and savagery, herding or barbarism, and civilization.

²⁷ Commenting on the origins of the eugenics movement, Gould asserts that 'Racial prejudice may be as old as recorded human history, but its biological justification imposed the additional burden

exhibited, with the purpose of charting Western man's (sic) inevitable rise to the pinnacle of humanity. This desire to exhibit and demonstrate (as well as providing popular entertainment) led, in the nineteenth century, to a number of people with learning disabilities being displayed in 'Freak Shows' as examples of 'foreign' peoples, supporting ideas about colonial expansion and social Darwinism. The study of 'Freak Shows', Bogdan (an anthropologist) argues, 'present an exciting opportunity to develop understanding of past practices and changing conceptions of abnormality, as well as the beginnings of a grounded theory in the management of human differences' (Bogdan 1982:2). He asserts that 'showmen constructed exhibits using people we would now call mentally retarded by casting them in an extreme form of the exotic mode' (ibid:119). Such shows were regularly visited by academics and the medical establishment who argued over the presentation of 'facts' by the showmen, which were often loosely based on available scientific data. What they did not question, however, was that these people so presented were indeed 'other', and therefore valid objects of scrutiny. For example, Bogdan refers to the exhibition of severely 'retarded' microcephalic siblings from Circleville, Ohio in 1860, who were fraudulently presented as 'The Wild Australian Children':

Described by showmen as members of a near-extinct cannibal tribe from the interior of Australia who had been captured by the explorer-adventurer Captain Reid ... Concocted publicity pamphlets; which were for sale at their appearances, emphasized that 'phrenologists and other scientific men' were of the opinion that they were 'neither idiots, *lusus naturae*, nor any other abortion of humanity, but belonged to a distinct race hitherto unknown to civilization' (Adventures of Three Australian Travelers 1872).

Ibid:120

of intrinsic inferiority on despised groups, and precluded redemption by conversion or assimilation' (Gould 1988: 31)

They became, Bogdan asserts, a very popular exhibit at freak shows, which had started to expand across America (and travelled to Europe), in the mid-19th century.

It makes sense, as Davis (1995) points out, that the early statisticians were also eugenicists. Sir Francis Galton, Karl Pearson and R.A.Fisher, for example, combined the notion from statistics that the population could be normed, dividing 'the total population into standard and non-standard populations' (Davis 1995: 30), with ideas from eugenics aiming to 'norm the non-standard' (ibid.). This, Davis asserts, is inherently paradoxical, 'since the inviolable rule of statistics is that all phenomena will always conform to a bell curve. So norming the non-normal is an activity as problematic as untying the Gordian knot' (ibid.).

Jahoda (1995:207), quoting a doctor who ran a large asylum early last century, notes that the eugenicists argued that 'imbeciles' would undermine the social fabric, as they were believed to be the most 'morally degenerate':

The recognition of the moral imbecile, and the absolute necessity of a life long guardianship, protection against temptation and all the horrors of criminal procedure, were strenuously insisted upon ... in the name of science, of sociology, as a matter of political economy, of the protection of homes, and all that man holds dear (Barr, 1904:1).²⁸

Similarly, Davis suggests that the notion held by eugenicists that 'individual variations would accumulate into a composite national identity was a powerful one' (Davis 1995:36). He adds that:

²⁸ The term 'moral imbecile' had several grades: 'Low grade ... temperament bestial (to) High grade ... with a genius for evil. (Barr, 1904 ,p.1)' (Quoted in Jahoda 1995: 207).

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One of the central foci of eugenics was what was broadly called "feeble-mindedness". This term included low intelligence, mental illness, and even "pauperism", since low income was equated with "relative inefficiency". Likewise, certain ethnic groups were equated with feeble-mindedness and pauperism

ibid.

During the late 19th and early 20th century, when the eugenics movement was at its height, there was a shift from an educational model, (pioneered from the late 18th century by the reformers Itard and Seguin), to a medical model in the treatment of people with learning disabilities, with the medical profession beginning to dominate the field. Jahoda notes, however, that the predominant concern was with 'the perceived threat of growing numbers of idiots and imbeciles who were considered to have abnormal sex drives' (Jahoda 1995:209). This led, Jahoda asserts, to the sterilisation (in the USA) of vast numbers of people with learning disabilities, even though the legality of this process was very questionable²⁹. At about the same time, charitable organisations were being set up, some along clearly eugenicist lines. For example, the *National Association for the Care and Control of the Feeble-minded* was set up in Britain in 1896:

It functioned as a pressure group advocating the lifetime segregation of 'defectives'. The group's emphasis on the prevention of sexuality and reproduction was motivated by middle-class fears about working-class fertility ... Charities originated from a perceived need to anaesthetize an ethically disturbing situation. The presence of large numbers of disabled people thus gave charities their raison d'être as organised assuagers of the bourgeois conscience.

J.Evans 1992:137

In the 19th century, asylums grew in size, as did the psychiatric profession which defined 'mental illness' and 'idiocy' and was in charge of admitting patients. As Scull

²⁹ See also Lifton's *The Nazi Doctors*, for documentation of medical experiments and sterilization of 'defectives' in Germany under the Third Reich. Similar sterilization programmes also occurred in the USA during the mid-20th Century and in Sweden up until the mid-1980s.

(1979) and Samson (1995) point out, they were thus creating a demand for their own services. Busfield, however, suggests that it was the English government and its Poor Law system, rather than the medical profession, that was responsible for the growth in asylums, as they became catch-all institutions for those who could not care for themselves. It is, however, most likely that the growth in asylums was due to a combination of factors. It is important to note that ‘power’ does not come from just one source, but is disseminated through cultural institutions, and does not solely reside in any one profession when it comes to defining deviancy³⁰.

The fact that a large number of people with learning disabilities in the West spent their lives in large institutions until relatively recently is undisputed. The exact date of the setting up of asylums, and the sequestration of people with learning disabilities, is somewhat contested³¹. Eayrs argues that, prior to the nineteenth century, most people with learning disabilities ‘lived as an integral (although not necessarily particularly valued) part of the community’ (Eayrs et al. 1993:67). Major changes, however, are documented as having occurred in the treatment of ‘idiots’ in the late 18th and early 19th century.

Scull shows how the ‘moral treatment’, advocated by Pinel and Tuke for those deemed ‘mad’, was influenced by religious ideas such as Quakerism, and became incorporated into the medical model with legal backing from the 1845 Lunatics Asylums Act and the

³⁰ It is important to realize that: ‘medicine is not capitalism, nor does medicine function in lockstep with the larger society within which it operates (Frankenberg 1980; Segal 1983). Medicine under capitalism is one thing (Navarro 1976a), but medicine as capitalism is problematic’ (L.Morgan 1987: 138).

³¹ See Appendix V

Lunatics Act. Similar movements for the ‘moral treatment’ of ‘idiots’ led by Itard and Seguin in the late 18th and early 19th centuries have been documented³². The segregation of many such people in asylums continued in Britain throughout the twentieth century. During my fieldwork, I met many (mainly elderly) people with learning disabilities, who had direct experience of institutional life and the social policies of the twentieth century. In the following chapters, specifically in Chapter 7, I look at Entelechy’s use of the arts as a medium through which to help these people make sense of their lives by constructing some sort of narrative or biography through which to relate their experiences.

From the mid-1950s onwards there was a marked change in social policy and attitudes towards people with learning disabilities, culminating in the ‘deinstitutionalisation movement’ and ‘community care’. Several well publicised scandals concerning the horrendous conditions in ‘mental handicap’ institutions in Britain and America in the 1960s and 1970s led to public enquiries, and the eventual closure of most of these places. Studies such as Goffman’s *Asylums* (1968) highlighted the grim conditions and oppressive regimes of mental hospitals and similar institutions, prompting reforms within British and American social policy, which aimed to treat the learning disabled as ‘people not patients’ (Jahoda 1995). Smaller *community*-based hostels were established as an alternative to the large asylums, and a concern with the ‘quality of life’ of people with learning disabilities became an issue. For example, patients were allowed to have their own property, such as clothes and toiletries: ‘However, these efforts at reform

were soon overtaken by the changing philosophy of care, which came to stress that people with mental handicaps had the right to live in home-like environments (Jay committee, HMSO, 1979)' (A.Jahoda 1995:209). During my fieldwork I came across evidence that this new 'philosophy of care' was not always implemented. For example, some of my learning disabled informants were still living in older style hostels, run along institutional lines. This appeared to be for financial reasons or staff shortages and bureaucracy, although staff working in these places were keen to assert that change was going to happen in the 'near future'.

This 'deinstitutionalisation movement' was fuelled by several factors, including critiques from reformers as well as financial motives from the state. However, Busfield (1986) suggests that another motive, which perhaps was more influential than the fiscal one, was the lowered status that the psychiatric profession had come to receive by being associated with asylums, and that by moving out into *the community*, their status would be raised. Most of what is known about the history of people with learning disabilities excludes the actual 'lived experiences' of those so defined, largely due to the fact that until recently their viewpoint was not taken into consideration, based on the presumption that they didn't have one. Recent social historians and social scientists have tried to redress this, for example Atkinson, Jackson and Walmsley (1997) have looked at the actual process of recording this history, suggesting that too much of the history of people with learning disabilities and the institutions in which they lived relies too heavily on official documents. Many social historians, they assert, assume that there was a national consistency in the experiences of people with learning disabilities in

³² See Appendix VI

Britain, which local studies are now questioning. Atkinson and colleagues advocate methods which involve a greater emphasis on oral history. As will be shown in later chapters, specifically chapter 7, Entelechy's work adds to a more 'grass roots' approach to the collection of such histories.

Clearly, the experiences of people with learning disabilities in Britain do not follow a smooth trajectory. There have been several attempts by social scientists to document the transitional stages of the position of disabled people in general within society. This is inherently difficult as it assumes a stable category of who should be classified as disabled, which, as recent anthropological studies mentioned earlier illustrate, is not the case. However, as has been shown in the above brief historical overview of ideas concerning the 'alterity' of people with learning disabilities in the West, complex discursive processes continue to influence how they, and the population in general, are seen as persons (or not), which is inevitably reflected in their treatment and the formation of social policies. This background has influenced the development of the social policy of *normalisation*, and the rise of libertarian movements such as 'disability rights', concurrent with the move by some social activists towards cultural intervention in the lives of people who have learning disabilities.

iii) Normalisation: Hegemonic Discourse and the Possibilities for Transformation

In essence, prevention and reversal of deviancy are what normalization (is) all about.

W.Wolfensberger 1972: 25

The prevalence of simplistic notions that normalisation meant 'to make people normal' led Wolfensberger to rename it 'social role valorisation', in an attempt to re-emphasise the centrality of supporting individuals in attaining socially valued roles rather than spurious conformity.

Brown and Smith 1993:xvi

While the normalisation project appeared to be radical, its assumptions were functionalist and its ideas and concerns interactionist (Chappell 1993; Oliver 1994). Such a project left untouched fundamental practices such as the professional control of services (Oliver 1994). Thus despite its apparent radicalism, the normalisation project could be relatively easily inserted into policy statements and practices.

Fulcher 1996:168

Much has been written about *normalisation* from a psychological perspective, which is not surprising as this theory is the brainchild of psychologists. However, what is surprising, considering the impact that *normalisation* has had on the day-to-day lives of people with learning disabilities in Britain and America, is that since its inception in the 1960s and until relatively recently, there has been very little critique of *normalisation*, either from within psychology or from other disciplines. Szivos (1993), a psychologist, suggests that this lack of critique may be due to the fact that words like *normalisation*, *deinstitutionalisation* and *mainstreaming* are functioning as 'flag-like symbols', demanding automatic salutes rather than thoughtful consideration.

Normalisation was originally a Scandinavian concept, which has been taken up by theorists in America and, later, Britain. Szivos (1993) and others have shown that the Scandinavian version (whose major proponent was Nirje), and the American version (largely formulated by Wolfensberger), have varying theoretical conceptions of 'difference' and the physical and social integration of people who have learning disabilities:

While Wolfensberger's definition has as its focus the normative images, competencies and behaviours demanded of people and their services, in contrast, Nirje's emphasis is on making available to people with mental handicaps normative patterns and conditions of everyday life (Nirje 1969) and on the individual's subjective experience of self.

S.Szivos 1993:114

Wolfensberger, an American psychologist whose version of *normalisation* (now termed *Social Role Valorisation*) has been very influential in Britain, asserts that the negative roles assigned to people with learning disabilities are reinforced through both unconscious and conscious imagery, which feed back into each other in a vicious circle. For example, if someone is expected to be incompetent, they are further stigmatised through others' attitudes and the way others interact with them. Wolfensberger has argued for the use of 'positive interventions' and 'behavioural techniques' to overcome apparent disabilities and social incompetencies. Jahoda points out that the 'theoretical backbone of Wolfensberger's ideas is that the general public ought to accept people with learning difficulties as valued members of the community through their conformity to social norms' (Jahoda 1995:210).

The main points of Wolfensberger's (1980) version of *normalisation* have been summarised by A.L. Chappell 1992: 36, as follows:

- a) the use of *culturally valued* means to enable people to lead *culturally valued* lives.
 - b) the use of *culturally normative* means to provide life conditions which are at least as good as those of the *average citizen*.
 - c) the enhancement of the behaviour, appearance, experience and status of the devalued person.
 - d) the use of *culturally normative* means to support behaviour, appearance, experience and status which are themselves *culturally normative*.
- (Adapted from Wolfensberger 1980b:8).

Wolfensberger borrowed a great deal of his ideas from Goffman, as Perrin and Nirje (1985) have pointed out. For example, Goffman uses the term 'pass' in his book *Stigma* (1963a) to refer to the normative social roles which stigmatised individuals have to acquire in order to conceal their stigmata. Similarly, the acronym used for Wolfensberger's service quality evaluation scheme, 'PASS' (Programme Analysis of

Service Systems), examined how far service provision for the learning disabled complied with the norms and values of wider society:

PASSING (Wolfensberger and Thomas, 1983) evaluation is the successor to PASS. It looks in detail at the service practice, the extent to which the services (are) an integral part of the local community, how much it conforms to social norms and whether or not it promotes a positive image of service users. The latter not only includes the ways in which the service users are presented (e.g. whether or not they wear colour co-ordinated clothing), but it also includes the presentation of staff members.

A.Jahoda 1995:211

Goffman defined 'passing' as the 'management of undisclosed discrediting information about self' (1963a:58). Deviancy and abnormality, Goffman suggests, are exacerbated or even produced through labelling. The individual behaves in accordance with the label they have been attributed, and to others' reactions to their label, thus 'amplifying' their deviancy. *Normalisation* attempts to change the circumstances under which interaction occurs, in order to make it more likely that 'non-disabled people will include devalued people in their activities. This process of increasing public tolerance of difference is an oft-ignored corollary of the normalisation approach' (McGill and Emerson 1993:75). In Wolfensberger's version of *normalisation*, disability is not 'spoken of as something which could be valued or accepted in its own right, nor are people who have disabilities able to be valued because of these qualities' (Szivos 1993:126). *Normalisation*, therefore, advocates 'passing' and adhering to societal norms, rather than celebrating (or even acknowledging) difference. Celebrating a 'culture' of disability - in other words, celebrating deviance from the 'norm' - would not be encouraged under this policy³³.

³³ Mat Fraser, a physically disabled performer, recently highlighted many of the issues and ambiguities around the representation of disabled people in a play about 'freaks' at the Institute of Contemporary Art, London, and how 'political correctness' and a 'zeitgeist of inclusivity' among liberal members of public did not necessarily prevent objectification of disabled people or an element of *schadenfreude*, deeply hedging the 'celebration of difference' with irony. For example, he expressed anger about the

‘Stigma symbols’, according to Goffman, are ‘signs which are especially powerful in drawing attention to a debasing identity discrepancy, breaking up what would otherwise be a coherent overall picture, with a consequent reduction in our valuation of the individual’ (1963a:59). For example, people with Down’s syndrome look visibly different to most of the population (they usually have epicanthal³⁴ folds), and are therefore automatically stigmatised. They are stereotyped as being very friendly, loving and docile, so when they deviate from this behaviour they are doubly stigmatised, firstly for looking different and secondly for acting in a way in which such stigmatised individuals are not supposed to. Wolfensberger has very controversially advocated plastic surgery for people with Down’s syndrome in order to make them less ‘stigmatised’. People with learning disabilities are identified as a group in need of *normalisation*, therefore they are not ‘normal’, hence the teleological dilemma of *normalisation*.

Wolfensberger’s version of *normalisation* promotes the idea that people with learning disabilities should conform to the most conservative social norms in order to be socially accepted, thus implying that such stigmatised individuals have limited choice as to how they express themselves. He argued that *normalisation* could be applied to any devalued group. However, as has been pointed out, this theory would be unacceptable to most minority groups as it advocates ‘adoption by them of the roles, culture and expectations of the dominant group’ (Emerson 1993:13). Simpson has argued that

pharmaceutical company which had manufactured the thalidomide that his mother had taken and which led to his deformity, at the same time as expressing a separatist sense of pride in his disability.

³⁴ A fold of skin over the inner canthus of the eye.

normalisation came into being as part of the attempt by psychology for ‘professional primacy vis-à-vis medicine’ (1996:99) in the field of learning disability. He asserts that *normalisation* is a ‘semi-autonomous discourse’, which has provided a vehicle for the appropriation of elements of contradictory discourses, namely behaviourism and interactionism: ‘The resulting configuration of power-discourse relations constituted a terrain in which new forms of subjectivity for “mentally retarded persons” developed’ (ibid.:100). Simpson adopts a ‘Foucauldian’ discourse analysis in order to understand the relationship between psychology and *normalisation*. He notes how in the 1950s and 1960s psychology began to restructure the definition of ‘mental retardation’, through developments in ‘adaptive behaviourism’:

The contemporaneous emergence of interactionist sociology was crucial for the subsequent success of Normalisation, and thus psychology, in promoting non-medical service models. Interactionist theories provided a basis for a political-moral attack on ‘institutions’ and the appalling conditions and effects on patients found therein.

Simpson 1996: 104

McGill and Emerson have looked at *normalisation* and applied behaviour analysis, suggesting that both approaches have influenced services in a purely symbolic way, re-languaging existing practices and procedures: ‘Thus, degrading and abusive reward and punishment regimes have become “habilitative behavioural intervention”, punitive seclusion has become “time out” and the dumping of people in “the community” has come to exemplify “the dignity of risk”’ (McGill and Emerson 1993:66). They ask the question of what happens when a ‘service user’ chooses to do something likely to damage their image or competence? Applied behaviour analysis answers that the choice is not free, and that the individual is presented with limited alternatives.

Normalisation's answer is to provide 'limited choices' of 'positive' alternatives, which are 'culturally normative'. This issue is returned to in Chapters 4 and 5.

Psychology became intimately involved with the *deinstitutionalisation* movement. This interest was concurrent with the desire within psychology to arrive at a more precise definition of 'mental retardation'. Simpson notes that the American Association on Mental Deficiency changed its definition of 'mental retardation' in 1958, shifting the emphasis from purely on IQ, to include 'adaptive behaviour'. This shift led to the proposition within psychology that 'mental retardation' was 'treatable'³⁵, making long-term institutional care obsolete³⁶. Simpson suggests that it was a:

Lack of ability to practice normality as a self-discipline which became the primary pathological feature of 'mental retardation'. The primary achievement for psychology was in securing the discursive strategy that it was a 'behavioural', rather than a primarily 'mental', deficiency which prevented the 'retarded person' from living a normal life.

Simpson 1996: 103

Numerous studies in the late 1960s and 1970s in psychology journals suggested that through the reinforcement of positive behaviour (and to a lesser extent, the discouragement of 'inappropriate' behaviour) the 'retarded person' could become accepted by wider society, and integrated into *the community*. *Normalisation* rhetoric,

³⁵ The growth of behaviourism within both Britain and America, Simpson asserts: 'helped stimulate a revival of psychological interest in "retardation". The development of this school's scientific theories and experiments in learning provided the basis for a "rediscovery" of the educability of the "retardate" (e.g. Tizard 1964). Interestingly, such claims were strongly reminiscent of the kind of claims that the pioneers of the scientific pedagogy such as Itard, had made a century previous ... Roos, for instance, claimed that: "[Man's] goal of eliminating culturally unacceptable behaviour has been brought closer to fulfillment during recent years by the systematic application of principles of learning" (Roos 1972: 137)' (Simpson 1996: 102-3).

³⁶ For example Tizard and O'Connor suggested that: 'most of the feeble-minded can live satisfactorily outside hospitals' (1956: 10).

therefore, suggests that all individuals are capable of ‘growth’ and ‘development’ towards some agreed point of ‘normality’.

Simpson argues that at an epistemological level the relationship between interactionism and *normalisation* is problematic, that is, the ‘idealist-subjective logic of interactionism’ is in conflict and contradiction with a ‘materialist empirical psychology which provided so much of the imperative force behind Normalisation’ (Simpson 1996:106). This contradiction is overcome, he suggests, through the roles, ‘which deviancy theories perform in Normalisation, i.e. as functions of discourse. Deviancy theories provided psychology with referential standards, a set of “norms” ’ (ibid.). This was important, he suggests, in allowing psychology to gain control of ‘mental deficiency’ from medicine. Some advocates of *normalisation* argued that it was the sub-culture of the institutions themselves which produced the deviance of the ‘mentally retarded person’ (in a similar way to the labelling theory), thus inverting the medical view that it was the pathology of the ‘retardate’ that necessitated institutionalisation. However, the transference of power from medicine to psychology did little to empower people with learning disabilities, and was, according to Simpson, ‘part of a wider strategy which both involved and resulted in the subjection of ‘mentally retarded’ people to other forms of domination’ (ibid:114-5).

Szivos suggests that Wolfensberger’s version of *normalisation* implies that through dispersing people with learning disabilities throughout a *community*, their self-esteem will become automatically raised as they mix with ‘non-deviant’ persons, helping them to feel more ‘normal’ about themselves. However, Szivos asserts that: ‘Although

Wolfensberger does not mention self-esteem (Briton 1979), without some such reference to subjective self-experience normalisation sounds hollow' (Szivos 1993:121). Szivos also asserts that evidence from psychologists using social comparison theory (e.g. Festinger 1954) suggests that disabled people who are dispersed throughout the population are likely to have low self-esteem, as it is:

Very difficult to compare oneself with others who are very different ... unless strenuous efforts are made to prevent it, people with disabilities in an integrated setting may find themselves in a situation in which a large proportion of the social comparisons they make will merely serve to confirm in them a sense of inferiority.

S.Szivos 1993:121

Tyne (1993) looks at the ways *normalisation* has been implemented in practice, asserting that it has been used in some instances to support independence training among people with severe disabilities who do not benefit from this and often fail.

Additionally, he asserts that:

Others still experience a great deal of boredom, frustration, and inactivity in community settings because this is seen as 'encouraging choice'... Others are placed into houses in which enormous attention is given to the setting and environment, but almost none at all to relationships and community membership, which may be seen as 'not our job'.

Tyne 1993:44

The actual impact of *normalisation* in the lives of my informants is touched on throughout the thesis. As will be illustrated in later chapters, particularly chapters 5, 6 and 7, Entelechy tried to negotiate both the incorporation of the ideology of *normalisation* (partly to secure funding from statutory services), at the same time as trying to move beyond it to create, within the context of avant-garde liberal aesthetics, a more radical and egalitarian praxis which was less oppressive to people with learning disabilities.

Simpson has pointed out that underlying *normalisation* is the assumption that, 'if reason is the basis for normality, i.e. sociability, then deviance is by definition the result and testimony of unreason. Those who cannot reason to normality, must be normalised since they are irresponsible for and incapable of choosing or achieving it for themselves' (1996:113). Hence my assertion that *normalisation* is inherently oppressive. Taking my lead from Foucault (1977; 1987), I suggest that the ideology of *normalisation* is an especially dense transfer point for relations of power. It is difficult to disguise bodies which deviate from cultural norms, either through disability, disease, or alternative sexuality. Such bodies remain symbolically undressed by both the medical and public gaze:

Normalcy, rather than being a degree zero of existence, is more accurately a location of 'bio-power', as Foucault would use the term. The 'normal' person ... has a network of traditional ableist assumptions and social supports that empowers gaze and interaction.

L.J.Davis 1995: 128

iv) 'Keeping it (corpo) real'

If, as Kuppers (2000) suggests, identity is about negotiation and performance:

Work on the social model of disability has reverberations beyond the issue of disability: it focuses on identity as a negotiated issue in the social realm, and on the body as core carrier of meaning. Traditionally, identity has often been used as a fixed attribute of an individual. Theorists such as Butler (1994) have put forward alternative ways of understanding social identity and the body, and have focused on the function of roles and performances in the social field.

Kuppers 2000: 119-120

In an article on the aesthetic invalidation of disabled people by the medical profession, Hughes has argued that the medical model of disability, which has until relatively recently been the dominant discourse on the disabled body, is far from benign, being based on the extrapolation that: 'bio-physical "maladaptation" - to use the ubiquitous

evolutionary terminology - leads to social maladaptation' (Hughes 2000: 555). Such a position suggests that 'the biological determines the social' (ibid.). The social model of disability challenges this: 'While the medical model demands that disabled people adapt to society, the social model demands changes in social structure that will reflect the needs of disabled people' (ibid.: 556). Michael Oliver (1988), a physically impaired academic, has been a major proponent of the social model. This position points to the medical profession's obsessions with 'cure', which for chronic disability is rarely a reality; and attacks 'rehabilitation', which may enhance the reputation of the profession, but does little in practical terms for the disabled, sustaining the idea of sickness and dependency. Hughes also criticises medical sociology, which, while taking on a social model of health, 'participated in the discourse which reduced disability to invalidism' (Hughes 2000:556), due to a tendency to look at impairment from an illness perspective (Barnes & Mercer, 1996:5). The social model advocated by Finkelstein (1980) and Oliver (1990) tried to remedy this by making a clear distinction between 'disability' and 'impairment'. The problem with this approach, however, was that it tended to focus on socially produced disablement, and neglected the actual 'lived experience' of physical impairment, almost taking it as a 'natural' given.

Despite the opposition to a 'social model' of impairment (as opposed to 'disability') by theorists such as Oliver (1996), Hughes argues that this approach will enhance rather than be detrimental to an 'unreconstructed social model of disability - to attend to a critique of medicine as culture' (ibid.: 557). His proposition, in a continuation of what he has argued elsewhere (Hughes 1999) is that, in the West: 'the oppression and alterity of disabled people is closely connected to the negative perceptual constitution of

impairment in the visual culture of post-modernity and that the medical gaze has been a key player in invalidating bodies that do not conform to its ideal discursive constructs' (Hughes 2000:557), and that by challenging the 'aesthetic of oppression', the medical model of disability is also challenged. However, other influences such as the growth and popularisation of psychology, and changing historical and cultural ideas about the 'ideal' body (outside of medicine) need also to be acknowledged.

The study of 'otherness', as mentioned earlier, is central to anthropology, and to other human sciences. Cultural representation and exclusion have been analysed using this concept of 'alterity' from Said's *Orientalism* (1978), to Shakespeare's (1997) examination of impairment, looking at the concepts of 'otherness, anomaly and liminality'. Hughes understands alterity as a process rather than a given, in which 'groups of people are pushed to the margins of social worth, and constituted as a threat to social order and a challenge to the integrity of the community' (Hughes 2000: 557-8). This process can be seen to be applied to both the physically disabled and people with learning disabilities (many of whom also have physical impairments):

The historical process of invalidating disabled people is fixed on the body (even with respect to intellectual impairment to which the 'rule' of biological reductionism applies) and our understanding of the body - what we think we know is true about it - is thoroughly medicalised.
Hughes 2000:559

In many respects, Hughes' position is very similar to that of the anthropologist, Mary Douglas, who argues that distinguishing between those who belong and 'outsiders' is very frequently done through 'the body'. Douglas asserts that the contours of 'the body' are established through markings that seek to establish specific codes of cultural coherence. She is suggesting, therefore, that the boundaries of the body become the limits of the social:

The Body is a model which can stand for any bounded system. Its boundaries can represent any boundaries which are threatened or precarious. The body is a complex structure. The functions of its different parts and their relation afford a source of symbols for other complex structures.

Douglas 1988:115

This implies that the limits of the body are never simply material, but that the surface, or skin, of the body is systematically used by society to signify taboos and the possibility of transgression. In *Natural Symbols*, Douglas suggests a theory of 'two bodies': 'The two bodies are self and society: sometimes they are so near as to be almost merged; sometimes they are far apart. The tension between them allows the elaboration of meaning' (1973:112). Essentially, her argument is that the body is a communication channel between itself and the social system, which acts on behalf of itself, and of the social system. She suggests that in order to explain why in one culture people behave in one way, and in another culture behave in a different way, 'culture' and 'nature' have to be seen as part of the same thing in relation to the social. In other words, Douglas develops a social theory of culture (as opposed to Mauss and Levi-Strauss who viewed 'nature' and 'culture' as different and opposite). Leading on from this, Douglas has argued that it was possible to predict the body techniques of a particular culture, if one knew the social organisation. She devised a theory of 'grid' and 'group' through which a particular social environment could be shown to produce a particular type of bodily behaviour. Her line of reasoning can be criticised for making a huge psychological generalisation, which is that people are happier in situations of consonance than in situations of dissonance, and that people are more at ease when a social, cultural and bodily configuration all fit together. The implication of this is that the dominant group in society which makes the rules will structure things so that concordance of style exists, and that the body is presented in an 'appropriate' way. This theory has striking

parallels with the ideology of *normalisation*, examined above. This view, however, presents a rather static view of society, which post-modernists such as Battersby (1993) and Haraway (1989) have shown to be inadequate, presenting instead a more fluid and dynamic view of 'the body' and society. Some sections of society will inevitably reject all or part of the grid/group configuration. Additionally, the body is not completely under the control of culture and society: for example, illness, disability and death introduce elements of uncertainty. Although Douglas has been criticised for over-emphasising the stability of 'the body', her ideas are useful in understanding how the 'disabled body' is conceptualised in the West. For example, a comparison of Douglas's ideas with the psychoanalytic tradition in Western culture - specifically the work of Freud, which has greatly influenced how bodily behaviour is understood in the West - clarifies cultural conceptions of disability. Particularly relevant here are Freud's ideas about 'projection', a process by which:

The qualities, feelings and wishes which the subject refuses to recognise or reject in himself or herself are expelled from the self and located in another person or thing. Projection, then, is splitting or denial of bad parts of the self. The unconscious transmission of ideology and the fear and hatred of difference is primarily defensive - an attempt to preserve the identity of the self.

J.Evans 1992:139

Davis suggests that most cultures 'perform an act of splitting (*Spaltung* to use Freud's term). These violent cleavages of consciousness are as primitive as our thought processes can be' (1995:129). He suggests that infants split their parent(s) into 'good' and 'bad' parts, later to reunite the parts of the parent as the child matures, although 'the residue of *Spaltung* remains in our inner life, personal and collective, to produce monsters and evil stepmothers as well as noble princes and fairy godmothers' (ibid.). Evans has argued that *Spaltung* is one of the processes occurring in disability charity

advertising which acts to alienate the viewer from the viewed. This is achieved, she suggests, through the people in the posters representing the split off parts of the viewer, 'imperfect, helpless, disgusting, shitty, dribbling - a threat to rigid ego boundaries' (J.Evans 1992: 139-140). Davis further suggests that most cultures tend to split bodies into 'good' and 'bad' parts, with some cultural norms being considered 'good' and others 'bad':

The psychological explanation may provide a reason why it is imperative for society at large to engage in Spaltung. The divisions whole/incomplete, able/disabled neatly cover up the frightening writing on the wall that reminds the hallucinated whole being that its wholeness is in fact a hallucination, a developmental fiction. Spaltung creates the absolute categories of abled and disabled, with concomitant defenses against the repressed fragmented body.

L.J.Davis 1995:129-30

Davis has additionally looked at the work of Lacan to provide another possible way of analysing the notion of the 'disabled body'. He suggests that Lacan's notion of the 'imago' or fragmented body parts, which form part of a human infant's consciousness, helps to explain the 'gaze' of horror, revulsion, and eroticism experienced when the 'able-bodied' subject views a 'disabled' object, it is as if the viewer is literally looking in a mirror and watching him/herself come apart at the seams: 'The disabled body ... is an entity from the earliest childhood instincts, a body that is common to all humans, as Lacan would have it. The 'normal body' is actually the body we develop later. It is a Gestalt ... Imaginary' (Davis 1995:140). He argues that the disabled body presents 'in both visual and tactile terms the rupture of the skin-ego, whether that disruption is lack of limbs or dysfunction of sensory organs' (ibid.:147). Drawing on the work of Anzieu (1989), he suggests that in the West, touching involves contact between one's ego with the ego of the object. This leads to a confusion of bodies, which, when the 'object' is a disabled person, is seen as both erotic and contagious. This assumes that 'normal' society 'needs' disabled bodies in order to feel psychologically whole. The argument is,

therefore, that we are all essentially fragmented, but psychologically, we convince ourselves that we are whole; unless, of course, we are disabled, in which case we can perceive ourselves as we 'really' are. Does this not attribute 'the disabled' with special, perceptory powers? Is it not more likely that people perceive themselves due to a combination of factors, according to social, cultural and historical variables, as well as the purely psychological? As put forward earlier, what 'disability' actually is is culturally and historically variable. This is not, however, to deny the materiality of the body, which, through impairment, radically affects how one experiences the World. These issues are explored in later chapters, particularly Chapter 5.

Davis redeems himself slightly by asserting that it is insufficient when analyzing the stigma assigned to certain bodies in a particular culture to look only at psychological explanations. He suggests that it is also necessary to look at historical data in order to understand that 'disability is a social process with an origin'. For example, in the West: 'Both industrial production and the concomitant standardization of the human body have had a profound impact on how we split up bodies' (Davis 1995:130). It is important, therefore, to move beyond structuralist/modernist theories such as Douglas's in order to understand contemporary conceptions of the disabled 'performing' body/self.

Christine Battersby (1993) has critically examined accepted metaphors of 'the body', suggesting some hypotheses of her own. She rejects the idea that 'the self' is simply located within and contained by 'the body', as writers such as Favazza (1987) have suggested. She argues that she does not see herself as contained within her body, and

that far from this being the result of some psychological disturbance, is in fact how many women experience themselves, backing this claim up with ethnographic evidence from a study by Emily Martin (1987). She suggests that the way forward for social theorists is to stop thinking about 'the body' as a three-dimensional container, and instead see it as in a state of flux, stressing 'potentiality, force, flow', rather than 'stasis and containment' (Battersby 1993:37). Battersby (1993), Haraway (1989,1991), and Butler (1990) argue that Western cultural constructs are not necessarily unitary. In the West, personhood, and therefore the body, they argue, are fluid and fragmentary, whether or not one is labelled 'other' (female, black, gay, disabled).

If, in post-modern society, everybody is fragmented, the implication is that everybody has the capacity to be 'grotesque', a 'freak'. Bakhtin's (1968) division between the 'classical' and 'grotesque' bodies should, therefore, no longer hold up. This, however, does not seem to be the case. Embodiment and physicality cannot be denied, unless we are all living in a permanent disassociative state. Some people are evidently more affected by their physicality than others. This is also the conclusion to which the social scientists Csordas (1994), and Shilling (1993) have come.

'Deviant' bodies are hard to assimilate in a culture which has entrenched ideal perceptual images of embodied personhood. They remain, to a large extent, objectified, whether they choose to 'perform' or not. The general public is unused to seeing disabled bodies in any other way. In order to correct 'abnormality', semblances of 'normality' are often sought and imposed in order to soften society's vision, for example through the use of prosthetics and through the surgical reassignment of

'hermaphrodite' infants' genitals. These practices could be loosely put under the term 'rehabilitation', closely aligned to 'therapy', which is the channel through which many disabled people, in particular those with learning disabilities, come into contact with the arts, and which runs against the aims of much of disability arts and radical theatre.

Hughes argues that the oppression experienced by disabled people is not purely about material 'facts', that is, it is not confined to the economic production of social barriers and restrictions: 'One must also take into account the cultural and aesthetic struggles of meaning and perception between disabled people and the powerful medical profession armed with the legitimate authority to name and classify impaired bodies' (Hughes 2000: 559). He suggests that the contemporary cultural process of what he terms 'the aestheticisation of everyday life' assists in emphasising contemporary forms of invalidation of the disabled. Drawing on the work of Davis (1995), who asserts that the concept of the 'norm' in a society inevitably leads to disabled people being seen as 'deviant', Hughes argues that:

This status may be amplified in a society where the somatic is central and judgement of social worth has become thoroughly aestheticised. This is the case in contemporary Western culture' Hughes 2000: 560

Obsession with 'the body' is not a new phenomenon, but the form that 'bodily awareness' takes is historically variable, and largely dependent on current perceptions of personhood. Shilling (1993) and others, have noted that the social significance of the body has shifted in recent times. In the past, Shilling suggests, the body was given meaning by national governments, whereas now, there is an increasing tendency for people to define their bodies as 'individual possessions which are integrally related to

their self-identities' (1993:30). Accompanying this change has been a 'crisis' in our certainty of what our bodies are. This 'crisis' has been reflected in art and literature, which is usually referred to as 'post-modern'. Shilling refers to Giddens' work on 'high modernity' (1991) to help explain this shift, in which Giddens argues that the self is now 'reflexively made'. It is evidently more difficult, however, for the self to be 'reflexively made' if the self entails a body which is dependent on others (cf. Lawton 2000). The 'social model' of disability, as described by Oliver (1990) places emphasis on 'the collective, structural, and social - as opposed to the individual, personal and medical' (Hughes 2000: 556). If seen in somatic terms, therefore, this is quite opposite to the model proposed by Shilling. However, the social model of disability deliberately steers away from the somatic, aiming to be more politically powerful by doing so. This leaves a large gap in the analysis, i.e. how can the experience of disabled embodiment be conveyed while still being political? The solution suggested by some is to develop a 'social model of impairment'. This is highly relevant in an 'aestheticized society':

The ubiquity of practices of aesthetic normalisation which fix around a shifting notion of the fashionable body constitute what Barry Glassner (1992) has called a 'tyranny of perfection'. In post-modern, aestheticised society the classical bourgeois value of bio-physical normality is displaced by the mytho-poetic 'virtue' of physical enhancement and somatic beauty. The potential for aesthetic invalidation is deeply inscribed in this cultural context.

Hughes 2000:560

The conflation of 'beauty' with 'goodness' (further explored in chapter 4 in the context of 'tragedy') has, as Hughes points out, long been occurring in Western culture.

However:

It is only in the image and information cultures of high modernity that the social has become saturated by the process of aestheticization (Featherstone, 1991b; Welsch, 1996). The centrality of the beauty myth in contemporary western culture has made 'aesthetic stratification as powerful as class, gender or ethnic stratification' (Synnott, 1993, p.101) and aesthetic relationships have become a significant factor in the oppression of disabled people (Hughes, 1999). Body surface or the 'presentational self' has become an important marker of social status and lies at the core of aesthetic discrimination.

Hughes 2000:560

Disabled people are not unaware of this and there exist counter-cultural arenas such as disability arts, where mainstream aesthetics can be challenged. Additionally, alternative aesthetics celebrating what is perceived by mainstream culture as 'grotesque' are also in existence (not necessarily performed by disabled people), which may be perceived by some as exploitative and voyeuristic, or by others as a legitimate expression of the variations of the human condition, for example:

When I begin to wish I were crippled - even though I am perfectly healthy - or rather that I would have been better off crippled, that is the first step towards *butoh*.

Tatsumi Hijikata, co-founder of the Japanese performance art/dance form *butoh*³⁷, quoted in L.J.Davis 1995:126

People with disabilities have been both displayed and sequestered throughout history. For example, Jenkins (1993) and Garland (1995) provide evidence that people with learning disabilities were employed as 'fools' for private or public entertainment. In the Roman period, Garland comments that, 'no fashionable household was complete without a generous sprinkling of dwarfs, mutes, cretins, and hunchbacks, whose principal duty appears to have been to undergo degrading and painful humiliation in order to provide amusement at dinner parties and other festive occasions' (1995:46). Garland also notes that human exhibits were placed alongside exotic animals in Roman 'freak shows', commenting that: 'it is not inconceivable that the seriously deformed were able to earn a modest living by exhibiting themselves to the public, just as they have done in recent times' (ibid.:55). How passive or active they have been in determining their own fate is evidently both historically and culturally variable, depending also on their social status. Street performance seems to have been one pervasive way of earning a living, displaying unusual bodily attributes, which still

continues today. Beggars 'performing' by exposing their amputations appears to be a tried and tested way of earning money, as attested equally by the 16th Century paintings of Brueghel or a contemporary walk through central London.

Recently, largely during the 1990s, the boundary has become increasingly blurred between what was previously categorised as 'disability arts' and other forms of performance. This has been due mainly to a resurgence of interest in 'the body' in society in general, as mentioned above, which has been reflected in 'the arts', and attempts have been made to break down the categories of 'able' and 'disabled'. Performance traditionally entails a dichotomy between audience and performer, gazer and gazed upon. The dialectic between 'subject' and 'object' in performance is a complex one. To say that the disabled body has been objectified historically (and, in many cases, continues to be so) is true, but oversimplifies the complex relationship between the body and society over time and across cultures and subcultures. The performing disabled body brings up further issues about representation, objectification, fetishization, power and control. These salient issues are currently being explored in the alternative arts movement, including many areas of 'disability arts', which may be grouped loosely under the term *avant garde*. The dialectics of audience/performer are brought into focus; for example, when processes of objectification are highlighted, making a 'spectacle of that which has already been made socially identifiable as deviant' (Little 1995:21). These issues are explored further in later chapters.

³⁷ Butoh is a dance form developed in Japan.

Fascination with the 'grotesque' runs somewhat contra to Hughes' view that modern society has only one aesthetic, which is the 'beauty myth'. This may be the dominant aesthetic, the 'body project' (Shilling 1993) to which many aspire, but the undercurrent of the 'grotesque' is also a powerful aesthetic. This differs somewhat from the subhumation of alterity, i.e. 'black is beautiful'. Shifting between voyeurism and decadence, the disabled body both serves as a metaphor for fragmentation of the post-modern self, while continuing to subvert such metaphorical usage through the insistence that the 'grotesque' is a lived reality, both contaminating, sometimes painful, but never receptive of singular 'objective' interpretation. The usage of disability as a metaphor for 'tragedy' in aesthetic discourse (particularly in performance) is returned to later in this thesis, specifically in Chapter 4. However, it is useful here to refer to two recent performances by disabled artists who imaginatively use this idea of the 'grotesque'. The first is by performers with learning disabilities, and the second by a physically disabled performer, both of which raise many salient issues.

The central issue for contemporary disability performance (in common with most post-modern performance) is that aesthetic strategies are used to inform a process through which spectators become aware of themselves. Both of the following examples aimed to do this through using the potent symbolism of the 'Freak Show'. The first performance discussed is by the theatre company, *Strathcona*, which in 1998 toured major cities throughout England. This was the sixteenth production *Strathcona* had put on, entitled '*id*', with all of the performers having learning disabilities. The play was set in an English circus, during the Victorian era: 'a time when ignorance and prejudice conspired to create the gaudy cruelty of the circus side-show. *Id* is about beauty and

the tyranny the image of beauty holds over the destiny of two babies ... A piece of physical theatre devised from original ideas by *Strathcona's* core company of eight learning disabled actors...'³⁸. The story revolves around twins separated at birth, one of whom is perceived as beautiful, and becomes very wealthy; the other is perceived as 'terribly ugly', and sold to a travelling freak show. As the story unfolds, the two characters are drawn together: 'The play asks the question is it right that people are treated better or worse because of what they look like instead of what they are like inside'³⁹. A journalist reviewing the piece refers to a previous review she gave of *Strathcona's* earlier production, '*Change of Heart*':

I was asked whether my enjoyment was real or feigned. If I found the question irritating, imagine how the actors must feel. Although it's a tender play, 'id' is full of anger at people's assumptions; its passionate attack on the beauty myth and the relationship between appearance and ability is simultaneously objective and utterly personal⁴⁰.

The argument in 'Id' that looks and feelings have no connection is criticised by the reviewer for lacking subtlety, although she praises the subversive use of an historical setting to highlight current issues affecting the disabled. Perhaps the most provocative element of the play is the desire expressed by the circus 'freaks' to take control of their destinies, realising the earning potential of their looks. The reviewer concludes by trying to fit the play back within a known, safe aesthetic: 'Like all the best fairy tales, and all the best people, much thought lurks beneath this appealing surface' (see footnote 40). Many of the dilemmas of learning disability performance are encapsulated within this play and the reviewer's response; in particular, whether or not to judge the performance according to 'normal' aesthetic values. These are explored further in chapter 4 and 5.

³⁸ From '*id*' publicity material.

³⁹ Same source as footnote 38.

⁴⁰ Extract from review of 'Id' by Maddy Costa, in Time Out December 16-30 1998

The second example is Mat Fraser's solo performance, '*Sealboy Freak*', performed at the ICA⁴¹ on 1st-3rd December 2000. Fraser is a physically impaired performer, whose repertoire includes kick boxing, drumming, acting, rapping, and TV presenting. This performance piece, devised and written by Fraser, was based around the life of a 1930s American freak show performer, 'Sealo the Sealboy' (aka Stanley Berent), who had similar disabilities to Fraser. In researching the piece, Fraser visited the last remaining US 'freak show', in Coney Island, New York, and was (to his amusement) offered a job.

Both performers had very short upper limbs (phocomelia), Fraser's being the result of his mother taking thalidomide during pregnancy: 'but his arms were shorter than mine, two models up, and more flipper-like' (Fraser⁴²). 'Sealo' earned his living in dime museums, demonstrating how he shaved himself and sawed wood in half, and also by selling his picture cards. Fraser states: 'I do all that and then explain the parallels between a modern disabled performer and the old shows ... (*I demonstrate*) ... feats of strength, drum 'n' bass, pornography and class A drugs'. Thus he asks the question as to whether a disabled performer can ever be perceived as anything other than a 'freak'. During an interview, Fraser commented that: 'When I wiggle my hands at the audience, I feel the primal power of the attention. And I can't help thinking: how fucking post-modern!'

⁴¹ Institute of Contemporary Arts, London.

⁴² From an interview in Time Out, November 29th-December 2000.

These two performances can be incorporated roughly within the view of disability culture as personal/aesthetic, advocated by Peters: ‘This view addresses decoding or recentering as an essential development of cultural identity, without which cultural enactment is a hollow exercise. Compared to Geertz’ notion of culture as symbolic action, webs of significance are spun through the human agency of disabled people’ (2000:594). Disabled bodies, therefore, are seen as sites of multiple meanings.

Hahn, in 1988, looked to historical evidence to pursue this line of enquiry, seeking an alternative aesthetic of disability, tracing a ‘subversive sensualism’ to the Middle Ages. This can be compared to Elias’s (1978) historical survey of changing attitudes to bodily processes, involving a transition from ‘*external constraints*’ to ‘*internal restraints*’ over time, termed the ‘civilizing process’⁴³. This entailed a shift in the perception of bodies being ‘open’ and ‘incomplete’, towards being ‘bounded’, separated off from other bodies (Elias 1978). This process has also been highlighted by Bakhtin (1968), who distinguishes between ‘classical’ and ‘grotesque’ bodies; additionally finding parallels in the rise of Western individualism, and its concomitant view of the person as ‘bounded’ and ‘autonomous’.

This ‘bounded’, ‘sealed’ idea of the Western person is culturally pervasive, and strongly affects the self-perception of many disabled people, whereby the disabled can feel at worst ‘ashamed’ of their bodies, and at best as something to be ‘managed’ as ‘flaccid, leaking and sensory deprived’ (Seymour, 1998:19). Post-modern performance, incorporating some areas of disability arts, however, makes explicit this

‘unboundedness’, incorporating the permeability of the body, using bodily fluids: for example the performance artist Franco B’s use of his own blood and medical instruments to produce a self-controlled and induced catharsis, and Stelarc’s use of computer technology to allow others to control his bodily movements through physical attachments to the internet. This sits uneasily alongside Hahn’s suggestion that disabled people can reclaim dominant aesthetic modes by deconstructing the body as a gestalt, emphasizing instead the body’s parts, thus cultivating: ‘a heightened aesthetic appreciation of anatomical variations’ (Hahn, 1988:223). This bears similarities to the proposition that ‘disability is beautiful’.

Such an approach raises questions of fetishization. The use of disability as a metaphor for deviancy is explored further in chapters 4 and 6. The decadent celebration of all things ‘bizarre’ (read ‘abnormal’/pathological) is not easily reconciled with asserting an aesthetic pride in the disabled body. Peters suggests that a possible way forward is to reconfigure ‘disability’ as subject, through a personal/aesthetic view, which ‘constitutes the performative self, which is strategic and positional’ (Peters 2000: 596).

v) Aiding the ‘Incompetent’ through Cultural Intervention

This thesis, as outlined in chapter 1, is predominantly concerned with examining a specific organisation which worked with people with learning disabilities in a ‘creative’ way. As this chapter has shown, throughout most of the twentieth century in the West, representations of disabled people have been produced by the non-disabled majority, most often within medical or charitable paradigms, and constricted within the

⁴³ See also chapter 6.

dichotomy of 'normal'/'abnormal'. This has had the effect of reinforcing the hegemony of non-disabled over disabled people, and it is this which the 'disability arts' movement seeks to address through reclaiming cultural representations, getting within aesthetics and changing them. The situation within Entelechy was fairly complex, as the company involved both disabled and non-disabled members. Which group asserted most aesthetic control was at times somewhat ambiguous, and the lines between 'cultural intervention' and 'disability arts' were not clearly drawn. This will be explored in subsequent chapters.

'Arts' as a 'leisure' activity for people with learning disabilities brings various responses (and attracts little funding⁴⁴). This is because of two underlying discourses: firstly, from an historical perspective, 'dependent' people in Britain are cared for because they are understood to be incapable of looking after themselves. They are perceived as reliant on 'others', and consequently are seen as not being fully 'adult' or fully 'human'. This has often resulted in their objectification. They receive aid and charity because in most cases they cannot work competently enough to be self-supporting financially⁴⁵. Apart from financial remuneration, the reward for work is to have some leisure time. Conversely, if no work is done, leisure 'should not' be allowed as a reward.

⁴⁴ As mentioned later in the thesis, much of Entelechy's funding came directly or indirectly from the Department of Health, and very little from arts funding bodies. Entelechy's facilitators spent large amounts of time engaged in drafting funding proposals, which were often unsuccessful. One source of potential funding which became available was the 'Arts For Everyone' grants, funded by the National Lottery. However, during my time with Entelechy, they did not manage to secure finance from this source.

⁴⁵ It needs to be noted that this is a perception rather than a reality. A large number of people with learning disabilities are engaged in some kind of employment, although this tends to be low status work, poorly paid, and productivity levels may be extremely low or non-existent.

This attitude was strongly reflected in the 19th Century Poor Laws which distinguished between the ‘undeserving’ and ‘deserving’ poor. It also reinforces the tenet that if leisure activities are engaged in by people with disabilities they should have some quantifiable purpose, most often envisaged through the paradigm of ‘therapy’, whereby individuals are somehow ‘improved’ or relieved of their symptoms. Many forms of arts therapies have very real benefits for people with learning disabilities, especially for people who have undergone traumatic experiences. However, the attitude that ‘arts’ equals ‘therapy’ where disabled people are concerned, has difficult consequences when they want to participate in ‘the arts’ for other purposes, such as for leisure or self-advocacy.

The second discourse relating to people with learning disabilities and their participation in leisure activities such as the arts, concerns notions of the ‘individual’. In some ways, it contradicts the first discourse. From a Foucauldian point of view, Western society’s focus on ‘the individual’ is inextricably bound up with the notion of ‘normality’, which is clearly reflected in the ideology of *normalisation*. As shown earlier, this policy advocates that people with learning disabilities should lead ‘ordinary lives’, and therefore take part in the same activities as the rest of the ‘normal’ population, including work and leisure, even if the work component of their lives is largely symbolic. *Normalisation* advocates ‘culturally normative’ activities for people with learning disabilities. On one level this could be seen as an attempt to protect them from engaging in degrading and humiliating activities or being exploited by others. On another level, *normalisation* can be interpreted as an effective mechanism for the dissemination of the dominant ideology/ies and the prevention of subversion, the latter

perhaps showing an awareness of the subversive possibilities of ‘the arts’ and in particular, ‘performance’.

It is apparent that both of these discourses are highly controlling. When ‘the arts’ are used as a form of ‘cultural intervention’ by social and cultural activists in the lives of people with learning disabilities, attempts are made at challenging the status quo, potentially opening up alternative avenues for exploring the representation and treatment of this minority group, contesting the boundary between ‘performance’ and ‘everyday life’. The locus of such activity in *the community*, in the light of such policies as ‘community care’ and the ‘community arts’ movement, are explored in the next chapter.

Chapter Three

‘Cultural Intervention’ in ‘The Community’: Welfarism, Learning Disability and ‘The Arts’

i) Introduction

What is ‘cultural intervention’ and why should socially excluded and marginalised groups, such as people with learning disabilities, be its focus? Does ‘disability culture’, or more specifically ‘learning disability culture’ exist, and does it possess any ideological tools with which to attack the status quo, or is this only achieved through the facilitation of other ‘enablers’? Why is ‘care’ now (supposedly) located in an entity called *the community*, and what is this *community* that cultural interventionists so often want to build or reinvoked? These questions are addressed in this chapter, which provides a theoretical basis for understanding the aims behind Entelechy’s work. I start out by providing a brief overview of anthropological literature on *community*, and suggest that an ethnographic approach is useful for this topic. I examine the notion of the ‘rational community’, looking at specific discourses stemming from the Enlightenment which influence current thinking on community care. Interventions by social and cultural activists are outlined, followed by an overview of such interventions with a sector of a ‘disenfranchised’ population in south-east London, providing an introduction to fieldwork data presented in subsequent chapters.

ii) *The Community*⁴⁶

In Britain, the word *community* at the close of the 20th century and beginning of the 21st represents a complex metanarrative which encompasses many contradictory ideas across the political spectrum. It has no single definition, but serves as an emotive icon which is multiply perceived. Some believe it to have ‘disappeared’, or is in need of rebuilding. It can be both a reference to something quintessentially ‘English’, a lost *gemeinschaft*⁴⁷ idyll, or to ‘local distinctiveness’⁴⁸, which, ‘While it is much concerned with architecture and local stone ... it also has to do with pre-modern cheeses, gas-holders, barred gates, kippers and increasingly scarce dialect words’ (Wright see footnote 48), It can refer to diverse inner-city areas, populated by supposedly cohesive ethnic, religious and ‘lifestyle’⁴⁹ *communities*. It has also become the locus (virtual or otherwise) in which the dependent sector of the population ‘should’⁵⁰ be ‘cared’ for. It is this last facet of *community* which I explore in this chapter, but which must be seen as influenced and embedded in these other discourses.

iii) Anthropology and *Community*

From an anthropological point of view, *community* is traditionally taken to mean face-to-face personal relations in a small-scale social network or residential settlement, as opposed to the more impersonal or contractual relationships characteristic of modern

⁴⁶ The term ‘*community*’ will continue to be referred to throughout this thesis in italics in order to emphasise its unstable and shifting definition, and its use in political rhetoric.

⁴⁷ See Tonnies (1957), *Community and Society* [*Gemeinschaft und Gessellschaft*, Leipzig 1887], East Lansing: Michigan State University Press.

⁴⁸ A term discussed by Patrick Wright at Common Ground’s Local Distinctiveness conference, September 1993, reported in *The Guardian* newspaper.

⁴⁹ ‘Lifestyle’ is a polite term of reference for groups of people whose behaviour would, in other contexts, often be referred to as ‘deviant’ by certain sectors of the population, i.e. homosexuals, drug users and the homeless.

urban and industrial society. Some more holistic ‘community studies’ have been attempted by ‘urban anthropologists’, for example Oscar Lewis’s (1965) study of ‘folk-urban ideal types’. However, these often tended to have a functionalist approach, and concentrated on intra-community dynamics to the neglect of wider power structures on the regional and national level, and their effects on *the community*. Hannerz’s (1969) study, *Soulside*, helped advance debate over the concept of *community* within the discipline by showing how: ‘culture can be a bridging concept linking local community life to wider macro-processes without falling into the traps of reification and cultural determinism’ (Howe 1990:53). Later approaches tended to concentrate on ‘symbolic boundaries’, for example the work of Cohen (1989), which suggests that such boundaries encapsulate a *community’s* identity. Instead of the Durkheimian *community* being an ‘integrating’ mechanism, Cohen suggests it is an ‘aggregating’ device, as people construct a ‘meaningful community’ through symbolic means. However, Cohen’s approach underestimates the complex ‘roles’ played by each ‘individual’, often crossing ‘boundaries’ and thus overlooking the complexity of ‘interfaces’. I intend to follow the suggestion that the role of anthropologist is to:

Look beneath the stated (or ‘imagined’ - Anderson 1991) community to examine the real nature of the ‘communities’ of which we speak, the localities with their kin, friendship, work and other social networks in which ‘welfare’ (glossed as ‘care’) follows its increasingly uncertain trajectory.

Edgar & Russell 1998:2

The concept of what *community* actually is in social welfare provision is extremely under-theorised. This, perhaps, if Skidmore is to be believed, is intentional: ‘The manifest function of community care is to provide a better quality of life. The latent function is to shift the responsibility for care provision. The process of empowerment

⁵⁰ Institutional provision still exists, and is seen as a place of containment for acute or chronic ‘cases’

by central government is linked to economy rather than needs' (Skidmore 1994:124). Therefore, by not defining what a *community* actually is, thorny questions regarding who actually does the caring and who is eligible to be cared for, can remain ambiguous or become lost in complicated legal rhetoric. *Community*, in this sense, is a widely meshed net which some 'vulnerable' people fall through or are inappropriately 'cared' for, due to a variety of factors such as inadequate finance or a lack of human resources. Each local authority is responsible for their quota of 'vulnerable' persons and, within tight budgetary constraints, tries to implement the optimum level of 'care' and 'control'⁵¹. As many of these vulnerable people fail to pass through life transitions which the so called 'normal' population take for granted (such as paid employment, marriage, parenthood), they become further and further alienated. Social and cultural interventions such as 'community development' and the 'community arts', which are examined in this chapter, seek to address, and perhaps reverse, some of this resultant marginalisation.

iv) The 'Rational Community'

The way people with learning disabilities have been and are still treated is related to complex historical, cultural, material and economic factors, which were examined in chapters 1 and 2. It becomes apparent, however, that, since the Enlightenment, and continuing today, their treatment is inextricably linked with two major discourses, namely 'rationality' and 'development'. It is evident that this history influences current social policies in profound ways, particularly that of *normalisation* on which the

who are at 'risk' to themselves or others, mainly those defined as mentally ill.

⁵¹ Particularly within services for the mentally ill.

majority of care for this sector of the population is now based. I argue that *normalisation* and a particular notion of rationality are bound up so tightly that it almost goes unnoticed, making it a very powerful ideological tool, acting to perpetuate the boundaries between people classed as ‘normal’ or ‘abnormal’.

These discourses on rationality and development are dependent on dichotomies such as nature/culture; male/female; and normal/abnormal. Such dichotomies are so pervasive in Western thought that thinking outside of them, as deconstructionists have tried to do, is extremely difficult. People with learning disabilities are associated with the ‘irrational’ side of the equation, in that they are viewed as more instinctual (‘natural’) due to the impaired functioning of their ‘minds’ and associated ‘abnormal’ behaviour. ‘Wild’ children have long fascinated the Western imagination. Individuals such as Kaspar Hauser and others, who were ‘discovered’ by civilisation and believed to have grown up with no human influences, were thought to represent the ‘wild’, ‘natural’ state of ‘man’ (sic). The fact that many such people are now believed to have been ‘autistic’ does not remove their status as ‘wild’ or ‘untamed’. Instead, the ‘wild’ is incorporated and controlled by being medically defined. It is the task of ‘therapists’ to reach out to these ‘incomplete’ persons, attempting to make them ‘individuals’, functioning in a normalising society. This, I suggest, is strongly conceptualised along Cartesian lines, described in chapter 2, which are that a person consists of a pure, rational mind (the intellect); a subjective, emotional mind (the will); and an instinctual but inalienable body. People with learning disabilities, by definition, have an impaired ‘intellect’. Consequently, they are governed by what Descartes termed ‘the will’, which is more prone to error than the intellect. Instinctual drives and bodily passions, therefore, have

to be contained and controlled by an outside agency as, according to this philosophy, people with learning disabilities are not capable of 'self-control'. Historically, as outlined in the first chapter, this has been done through sequestration and incarceration, with the imposed 'intellect' taking material form in the guise of the walls of the institution. The sexes were separated to prevent the reproduction of more 'undesirables', and sterilisation⁵² helped control the consequences of any unchecked 'bodily passions'. Shifts in policy towards 'community care' have meant that other 'rational' individuals such as social workers, nurses and therapists, are required to take on the role of the 'intellect', and these coerce, guide and control 'the will' of the learning disabled. For example detailed policies, based largely on behaviourism, are implemented to deal with what has been termed 'challenging behaviour'.

A further dichotomy, that between 'arts' and 'science' is relevant here. The 'arts' are traditionally seen as more emotional, subjective, 'irrational', whereas 'science' is subjective, 'rational'. This leaves the place of 'therapy', especially those forms based in 'the arts', in an ambiguous position. Seeking validation, 'therapists' frequently use the terminology of scientists to declare their efficacy⁵³. In recent years attempts to bridge this gulf and, to an extent, marry the two approaches, has resulted in funding from science-based institutions such as the Wellcome Trust going towards arts-based ventures such as theatre-in-education in order to aesthetically explain 'science' to the 'public'.

⁵² See Thompson 1996 for an historical overview of sterilisation policy in Britain.

‘Arts’ for, with and by people with learning disabilities are inevitably caught up within therapeutic paradigms. The pathologisation (albeit within behavioural terms) of learning disability demands ‘treatment’, even though there is no ‘cure’. ‘Arts for arts sake’, would, according to the Cartesian philosophy outlined above, reinforce this group’s ‘incompetency’, as it would be reinforcing their ‘emotional’ proclivities. Indeed, much of the work of Entelechy described in this thesis has been criticised at one time or another by representatives of professions such as psychology and social work for exactly this, failing to provide neither ‘age-appropriate’ (i.e. normative, ‘developmental’) activities, nor adequately controlling ‘challenging behaviour’. At the same time, ‘service providers’ are required to maintain a certain standard of ‘quality of life’ for these people which, one would hope, might entail the enjoyment of some degree of pleasure. Their status as autonomous ‘individuals’, capable of choice, is, therefore, left in question.

Due to their questionable personhood, ‘interventions’ (or rather ‘ideologies’) in the form of social policy have emerged to ‘assist’ people with learning disabilities (and the mentally ill⁵³) to function adequately in, what I have termed, the ‘rational community’. The core idea is that the ‘abnormal’ can be assisted to behave in a ‘normal’ way, and thus become an accepted and valued member of *the community*. Hence the emergence of *normalisation*.

⁵³ Current debates surrounding the merits of psychiatric drugs (rational, scientific) as opposed to ‘talking’ therapies (subjective, emotional), in the treatment of conditions such as anxiety and depression attest to this.

⁵⁴ This thesis does not address the issues relevant to this sector of the population, although their perceived ‘irrationality’, and their temporary or permanent removal from *the community* when this becomes disruptive or presents unacceptable levels of ‘risk’, has some relation to the treatment of people who have learning disabilities.

v) Community Care

As described previously, largely as a consequence of the NHS and Community Care Act 1990 in Britain, over the past decade thousands of people with learning disabilities who were long-term residents of large institutions have been moved into *the community*. Unfortunately, 'there is not necessarily a community to go to' (Evans 1992:137). Evans argues that 'While "mental handicap" is constructed as "other" and this "other" appears to be a threat, then the non-disabled "community" is likely to perceive the presence of people with learning disabilities as a threat' (ibid.). She notes that in a MORI poll conducted for Mencap⁵⁵ in 1982, 62 per cent thought 'mentally handicapped' people should be cared for in the community and 23 per cent thought that they should be segregated in schools or hospitals' (Evans 1992: 137-8). However, about 50% of these respondents expressed a wish not to live in proximity to people with learning disabilities: 'Thus, it seems that even when people are in favour of dismantling institutional provision, the "community" into which disabled people are meant to go is located "somewhere else"'. Here, "the community", as an internal object in people's minds, operates as a metaphor for imprisonment' (ibid.).

The general public's attitude to 'community care' does not seem to have changed much over the last 19 years, and I was aware that several of my informants who had learning disabilities were harassed by their 'normal' neighbours. The juxtaposition of the words 'community' and 'care' appears to be an oxymoron. An alternative idea of 'collective

care' in the *community* (as opposed to in institutions), thus removing the 'burden' from 'individuals' (that is, predominantly female carers), has been explored by Dalley (1997). In a revision of an earlier article on the subject, she incorporates viewpoints from disabled writers such as Morris (1991), who assert that 'care' should be seen as 'caring about', rather than 'caring for' disabled people. Morris and other disabled commentators advocating a social model of disability have also argued for:

Economic and financial autonomy. Instead of being provided with inadequate services, allocated by uncomprehending professional state employees, disabled people want to receive cash allowances with which to buy the personal assistance they themselves choose. Only in this way, they argue, will they be able to live independent lives - independent in the way they define independence (Morris 1993) - in control of their life circumstances.

G.Dalley 1997:156

Dalley, following Shearer (1982b), importantly points out that dependence and interdependence form part of daily life for the whole population, rather than those identified as somehow more 'needy' than others. Additionally, however, she shows that the heterogeneity of 'dependence' should not be ignored, with different people having very differing needs. Class, 'race' and gender play extremely influential roles in the distribution of 'care' in *the community*, as several studies have revealed (e.g. Gunaratnam 1997; Graham 1997). Wolfensberger's ideal of dispensing with 'paid carers', building a society (or, rather, *community*) based on altruism seems at best naive, and at worst exploitative. Complex issues around the receipt and delivery of 'community care', including the views of all those involved, need to be addressed. In my research group of people with learning disabilities, few people were able to articulate in the language of service providers (or, sometimes, any recognisable language) their needs and desires. Consequently, others made many decisions for them.

⁵⁵ Britain's major charity for people with a learning disability, established in 1946.

One of the aims of Entelechy was to assist in this articulation, through various aesthetic media, as I have already indicated. Although acknowledging the very prominent part that paid social service and other carers (including unpaid carers) play in the lives of people with learning disabilities, this is not the focus of my study.

It is useful to state what the government actually meant by 'community care'. The following extract from a Department of Health leaflet printed in 1993 offers one definition:

Some people cannot manage on their own without help. Community care means helping them to live in the community in their own homes or sometimes in sheltered housing or in a residential care or nursing home. Family and friends give most of this help⁵⁶.

Help also comes from:

- local authority Social Services Departments (Social Work Departments in Scotland) through, for example, special housing, home care or home help services, meals-on-wheels, day care and residential care;
- residential care and nursing homes;
- voluntary or private organisations providing care in day centres or people's own homes. These are sometimes called "community care services".

The NHS also provides community care help through, for example, a family doctor, physiotherapist or district nurse.

This shift in social policy away from institutional 'care', explored briefly in chapter 2, is described by Taylor as part of the political re-thinking of the idea of the welfare state:

With the advent of a radical right-wing Conservative government in 1979 came a major challenge to the welfare state ... The welfare state was held to have eroded individual and community responsibility and to have allowed the interests of providers to dominate over those of consumers. Over three terms of this government, policies were introduced to reduce the State's responsibility for service provision and, as far as possible, for finance. Although the major policy changes did not take place until the third term, the directions were clear from an early stage.

M.Taylor 1997:336

During this era, Taylor notes, precedence was given to economic regeneration, with the idea that wealth would filter downwards through society. This was accompanied by the decentralisation of decision making and service delivery, through: 'encouraging public

authorities to contract the delivery of services out to independent providers and introducing opportunities to take services out of local and health authority control. Where independent delivery was less likely, the purchasing and providing roles of authority were separated to form an internal market' (ibid.). Behind this, Taylor asserts, was the desire to create a 'mixed economy of welfare' with increased 'choice' and 'accountability' for the 'consumer' and *community*. The ultimate aim was, she suggests, to reduce the financial burden for welfare provision on the State, shifting the responsibility to 'individuals' and 'families' through 'active citizenship' (ibid.). A greater emphasis was placed on utilising resources from charities and voluntary sector organisations, turning to the State in the last instance⁵⁷.

Modern post-industrial Britain could be described using Durkheimian terminology as a 'complex' society, characterised by impersonal relationships. However: 'Policies such as "community care" ... are premised on a view of society that emphasizes its "simple" characteristics - the face-to-face, family and "community" relationships in and through which "care" is primarily situated and performed' (Edgar & Russell 1998: 2). Edgar and Russell suggest that the creation of the policy of 'community care' was largely an attempt in 1970s Britain to:

⁵⁶ As many critics have pointed out, family is a euphemism for 'women'- see Bornat et al (eds.) 1997.

⁵⁷ This was 'encouraged' through the introduction of benefit cuts, especially for young people, and the introduction of the Social Fund' (Taylor 1997: 336), access to which was restricted even for those in greatest need.

Create something of an opposing ideology to prevailing views of what a 'welfare state' is or should be. 'Community care' articulates a romantic, *gemeinschaft* view of 'welfare' and where it will be located. In Britain, 'community' is often pictured in opposition to the state, something which has just disappeared but which, with a little more effort, might be found, or developed, again. It is often used as a gloss for the sometimes chimerical diminution of the powers of the state in favour of local control.

ibid.

In this thesis 'community care' will be viewed as a localised form of welfare provision, specific to Britain. As the role of the State became that of primarily a funder, it purchased services from a variety of private, public and voluntary organisations, creating competition for contracts. Social services became the commissioning agency (purchasers) who assessed, organised or acquired and planned for the needs of the population requiring 'social care'. Services actually delivering 'care' are referred to as 'providers', and these can be a mixture of statutory and private or voluntary agencies. The work of Entelechy needs to be seen within this mixed economy of welfare. Entelechy, a *voluntary sector* organisation, worked in partnership with social services and community support agencies. Its main commissioning agencies in the mid to late 1990s were Southwark Consortium (later renamed Choice Support), Lewisham Partnership, Lewisham Arts Service, Lewisham Leisure, Lifestyles and Joint Finance, representing a mixture of local, social and health authority agencies in the area⁵⁸. Additional funding came from charitable trusts and donations, as well as a major grant from the Department of Health to support the 'Rediscovering Our Histories' project (see Chapter 7). In late 1998, David Slater (Director of Entelechy) explained Entelechy's then current sources of funding:

We are funded mainly by money directly or indirectly routed through the Department of Health for people with learning disabilities ... which is about 70-80% of the funding ...

⁵⁸ During the course of my fieldwork, there were some shifts in the commissioning agencies, but they remained roughly the same throughout this period.

a small amount comes from the local authority; project work is sometimes funded by regional arts board, and then a collection of small trusts give donations, which is the way most voluntary sector groups are funded.

Drawing its funding from such bodies implies that Entelechy provided some sort of 'service' or 'care' which fitted into budgetary remits. The suggestion is, therefore, that Entelechy, and other such 'voluntary sector' initiatives were providing something which statutory services did not. According to Skidmore, such organisations are 'an indictment that the health service has either deserted them ... [*i.e. people in need of care*] ... or failed to provide an effective service. On an economic level ... [*they*] ... are an excellent alternative to formal services because they negate the need to provide services in the future' (1994:98).

vi) Cultural and Political Interventions in *The Community*

The late 1960s counter-culture was a major stimulus to, and a partial source for, the ideological orientations of the great emancipatory and libertarian movements of the 1970s and 1980s. These included the gay rights and black consciousness movements, the women's and feminist movements, the community activist movement and the various movements that fought for the rights of people with disabilities, the elderly, the hospitalized, and other types of socially disadvantaged group, and it may include even the campaign for a popular, grass-roots-based culture that was fought in the mid-1980s.

Kershaw 2000:141

Kershaw, a director and performance theorist, does not argue that the counter-culture of the late-1960s actually 'caused' the emancipatory and libertarian movements mentioned here. He suggests that they have their origin in 'a widespread and continuing dissatisfaction with the inadequacies of late-capitalism in providing for the needs of minorities and marginalized groups' (ibid.). However, what it did provide was a 'model' for: 'oppositional action against hegemony, on a grand scale' (ibid.). The question is raised, however, as to how such a diverse counter-culture could produce a coherent ideology. Kershaw answers this by drawing on the work of Roszak (1969),

who: 'identifies the ideological foundation of the counter-culture as an opposition to hegemony by a utopianist idealism which promoted an egalitarian ethic through the advocacy of participative democracy on a localized level' (Kershaw 2000:141). The effects of this ideology will be shown to be still clearly existent in the work of Entelechy.

Thatcherism emphasised the notion of the 'individual' and 'market forces', and was generally against collective action, immortalised in Thatcher's words: 'There is no such thing as society, there are individual men and women, and there are families'⁵⁹. However, as Taylor notes, conflicts between local and central government in the 1980s gave rise to renewed interest and investment in 'community development': 'as local authorities began to decentralise services and cultivated local support through funding local community initiatives' (1997:337), with the Greater London Council being particularly forthcoming with funding for minority groups. Interestingly, Taylor observes that:

Many local authorities funded their critics at this time, but it could be argued that community organisations and local government were ultimately on the same side. Community organisations rarely sought to replace public services. Instead, they saw themselves as forcing public services to be more accountable and more sensitive to need, through providing advice and advocacy, through lobbying for improvements in services, and through demonstrating how services should be providing for their constituencies.

Ibid.

In parallel to this, Taylor notes, was a recognition from those advocating 'community development', that *the community* was actually very diverse, especially in inner-cities, and more sensitive and culturally specific approaches were needed. Towards the end of the 1980s, however, funding for such developments diminished considerably. This,

⁵⁹ Quoted on 31st October 1987 during an interview with the magazine *Woman's Own*.

Taylor suggests, was largely to do with the abolition of the metropolitan counties and increasing financial pressures on local government, exacerbated by the introduction of the poll tax, which led to widespread cuts in order to avoid ‘capping’ of the charge by central government. The consequence of this was a change in emphasis in many *communities* from ‘seeking improvements to protecting existing services’ (ibid: 338). Community development projects began to look towards Europe for funding, for example, from the European Social Fund.

One result of all these changes was an emphasis on the consumer and the ‘quality’ of service provided. This has begun to take the form of involving consumers in decisions, and the current emphasis on ‘user empowerment’. This may, however, be purely rhetoric, and ‘user empowerment’ may become overridden by the new managerial structures, as Littlewood illustrates:

In a further move from biomedical empiricism to marketing, the preferred language has shifted recently from *unmet needs* (the illness and its social consequences as assessed by professionals) to *unmet choices*: desires articulated by the apparently not disabled patient as consumer yet only to be assessed as *fundable* (legitimate) by the manager.

R.Littlewood 1999:410

Prior to, and in parallel with these political interventions in *community* were what can be termed ‘cultural’ interventions, based on the idea that it is possible to build or regenerate *community* through aesthetic means. Throughout the twentieth century certain groups of ‘radical’, or ‘revolutionary’ artists have sought to attack the social hierarchy by aesthetic means, predominantly through ‘performance’. One such form this took was ‘agit-prop’, which is:

A militant form of art intended to emotionally and ideologically mobilise its audience to take particular action vis-a-vis an urgent social situation ... In the early twentieth century, agit-prop was a left-wing project looking to communism for answers and addressing the working class ... Although drawing on a range of theatrical genres, the quintessential agit-prop piece was short in length and broad in concept, sharpening class differences and simplifying class warfare into a battle between an idealistic worker protagonist and a top-hatted, cigar smoking capitalist antagonist.

J.Cohen-Cruz 1998:13

However, as both Kershaw (1992) and Cohen-Cruz (1998) point out, seeing agit-prop in purely Marxist terms is problematic. According to Kershaw, clear divisions in Russian, German and British societies in the 1920s and 1930s, cannot be compared easily with the situation of social upheaval in Britain in the 1960s and 1970s, which was the formative period for much 'radical' and 'alternative' art. This is because:

In conditions of cultural pluralism produced by political consensus, relative affluence and the ameliorating force of the mass media, the agit prop form becomes problematic ... partly because the chief oppositional formations - the counter-cultures - are not all programmatic in their ideologies, making any kind of didacticism difficult. And it becomes doubly problematic because in a pluralistic society the 'enemy' to be attacked is not easy to identify.

Kershaw 1992:80

Cohen-Cruz suggests, however, that agit-prop can be used in 'culturally pluralistic' societies as long as it is understood that, firstly: 'as social contexts become more complex, agit-prop may serve an educational function around a specific issue, not necessarily advocating general revolution' (1998:14); and secondly, that the actors should believe in the answer to a specific social problem, and be prepared to engage in the same 'revolutionary' acts or solutions which they encourage in their spectators. The potential for 'performance', in particular, to transform societies or individuals is discussed here, and also in later chapters. However, I suggest that over recent decades, much of this social and political 'aesthetic' activity has become distilled in the West, particularly in Britain, and now exists at a less radical level, informing what has come to be known as 'community arts'.

‘Community arts’ and ‘community care’ emerged more or less in tandem. David Slater touched on this issue succinctly in an interview, saying: ‘there seemed to be lots of cross-overs between the language that was appearing in learning disability services and arts in the community.’ This would indicate, therefore, that both ‘movements’ share similar ideas as to what *community* really means, although the actual situation is fairly complex. ‘Community arts’ are very much based on liberal ideas about ‘grass roots’ social and political action, although they are usually accompanied by paternalistic ideas concerning an outside agency (arts practitioners) going in and stimulating activities, rather than consolidating an existing self-generating movement. As the example of Rotherhithe Theatre Workshop mentioned below shows, when outside support is withdrawn, activities often cease.

vii) Community Development and the Arts

The political upheaval and activism of the 1960s and 1970s in Britain, France and America led to a spawning of ‘agit-prop’ type arts companies, many of which staged impromptu and carnivalesque gatherings. Most of these touring companies tried to operate at a grass-roots *community* level, later settling down in specific *communities*, thus fuelling the ‘community arts’ movement⁶⁰. Schechner’s (1991; 1998) critique of the carnivalesque, including examples from the pro-democracy movement focused in Tiananmen Square and the fall of the Berlin Wall, suggests that ‘carnival can critique but not replace the status quo’ (Cohen-Cruz 1998:168). However, Kershaw’s study of the British performance company ‘Welfare State International’, examined by Cohen-Cruz, suggests that by finding a permanent home in a *community*, they are ‘following a

different mode than carnival as a temporary suspension of the status quo. They are looking to weave celebrations into the everyday life of their towns' (ibid.). Entelechy's agenda clearly reflected these aims, with moves towards 'cultural recognition' and inclusiveness in local *communities*, encouraging the quotidian to shape and inform practice.

Core members of Entelechy Arts (namely David Slater, Rebecca Swift, and Mara de Wit) trained at Dartington College of Arts, based in Devon, England, which was a central location for the development of 'community arts', and this obviously influenced their later practice.

In April 1983 Dartington College held a week long conference entitled 'European Workshop on Theatre and Communities', which was attended by arts practitioners, students, social activists and academics⁶¹ from across Europe. The aim of the conference was to discuss, debate and disseminate practice around a recently emerged phenomenon across Europe, namely 'community arts'. According to de Wit, 'community arts' was established in Britain in the 1970s, taking its lead from the 'experimental third year community scheme' at Dartington College of Arts, during which students went on placements in inner-city areas. The college provided courses leading to degrees and diplomas in the arts, and was specifically renowned for its emphasis on contextualising the 'arts' within society:

⁶⁰ See Appendix VII

⁶¹ Including the theatre practitioners/social activists Augusto Boal and Eduard Delgado; as well as the anthropologist, John Blacking.

During the 1970s, along with the democratisation of culture, a shift took place from amateur arts to community arts practice ... The Dartington placement scheme coincided with the setting up of the first Community Arts Committee by the Arts Council for a two year experimental period ... The Dartington programme befitted the 'arts in a social context' movement.

de Wit Unpublished

The proposed aim of the conference, stated in their summary report (December 1983), was 'to express the contribution theatre practice can make to the welfare of the community in which it occurs'. Dartington's degree and diploma courses actively encouraged the cross-fertilisation of ideas between social science and arts practice, and tried to integrate 'non-Western' approaches.

The 1983 Dartington workshop was based on a belief that: 'theatre, and the performing arts in general, are part of the infrastructure of human life. It is acknowledged that they are only one of many such human activities but, if properly explored, they have the power to enhance consciousness and liberate human potential.' (Summary Report, p.8). During the week of seminars and workshops, many themes were discussed, and it became apparent that there was no one definition of what *community* meant. For example, did it refer to a geographical location or a group of people connected through common interests and concerns? What clearly emerged from the discussions, according to the summary report, was that:

There is occurring at present throughout Europe a massive realignment of theatre activity in relation to society. The languages of theatre activity, as a means of communication and celebration, are being employed by people within a wide spectrum of societal activity.

Summary report 1983:8

Additional findings of the report suggest a desire by theatre practitioners to increase a feeling of 'relatedness' amongst those with whom they work. The conference members had difficulty in defining what this idea of 'relatedness' actually meant, although the report suggests that, 'it appears to involve aliveness, being in touch with feelings and

attitudes, and being present to one another in shared experience and shared problems. We might also speak of being natural and spontaneous' (Summary Report 1983:23)⁶².

From this report, it appears that European 'community theatre' activities in the 1970s and 1980s were based on an idealistic concept of *community* which could be achieved through social action or cultural intervention by theatre practitioners. This search for a *gemeinschaft* type of 'relatedness', as described by Tonnies, was in keeping with the social and political ideals of the 1960s and 1970s, which evidently informed their practice. The conference members were not unreflexive, however, and decided that it was impossible to define *community* adequately, suggesting instead that 'Perhaps it is almost better to say that a community in the traditional sense hardly exists in modern industrial Europe except in isolated rural pockets' (Summary Report 1983:25). This still implies that there is some core idea of what they believed *community* to be. The writers of the Summary Report turned to anthropology for a clearer definition of what this sense of 'relatedness' was that they were trying to achieve:

Whenever people have the sense of being alive and wholly present to one another we have the 'spirit of community'. The anthropologist Turner called this process of being wholly present and alive 'communitas'. Without 'communitas' the cycle of daily routines and repeated acts lacks authentic energy and people cease to be able to take care of the world because it is no longer their world.

Summary Report 1983:25

What the report writers and conference delegates seem to be arguing, therefore, is that cultural intervention is needed where there is a sense of alienation. Indeed all of the groups with whom these theatre practitioners worked, or aimed to work, were the disenfranchised, the marginalised and the excluded. Is this aim of seeking to build

⁶² See Appendix VIII

community (or, perhaps, 're-build') an effective form of social and political action? How successful is it in attacking the status quo? Is, in fact, a desire to build harmonious relations among those in 'inner-cities' or other potentially impoverished and troubled areas, supporting the dominant structures of the State?

viii) Community Arts Interventions in the London Docklands

London Docklands has been the location of 'community arts' practice since the 1970s, due to the arrival of Dartington College of Arts students on placement in 1975 and 1978 at the Rotherhithe Theatre Workshop (RTW)⁶³. This neighbourhood was described by de Wit as then being in:

(An almost delayed post-war) decline and malaise, with a high unemployment rate due to closing down of local industries and the end of known ways and means of sustaining people's livelihoods ... Yet, the neighbourhoods and these communities were on the brink of radical transformation. As designated areas of urban regeneration, changes were underway which would bring in a whole new population, with different lifestyles, ambitions and needs.

Mara de Wit, Unpublished

Mara de Wit, a core member of Entelechy at the time of my research, recently completed a PhD thesis on dance practice developed at Dartington between 1971 and 1987. Her thesis included research on Dartington's 'community arts' placements in inner city areas. One such placement, the RTW is of interest here as it was in the same locality where much of Entelechy's work was based in the 1990s: 'RTW was based in a converted four storey warehouse, facing the Thames ... This was dockland area in limbo, with a still tightly knit, but somewhat disenfranchised community, no longer credible as a viable working community, with the docks closed down, the river quiet and acres of disused land' (Mara de Wit, unpublished). De Wit argues that the idea of

⁶³ Source: de Wit – PhD unpublished.

establishing 'community arts' in such an area in the mid-late 1970s appealed to the local authority:

Stimulated by the 'zeitgeist' of social democracy, the Dartington students (and staff), ready to engage in 'more art of people and less art for people'... brought in a new energy and creative possibilities ... in the borough of Southwark, Dartington College of Arts was accommodated with (relatively cheap) studio space and hard-to-let flats leased to the students. This truly enabled living and working in the community and stimulated the creation of estate-based events and activities ...

de Wit Unpublished

Tutors and students from Dartington and visiting artists co-ordinated various projects, engaging with members of *the community*, with students taking the arts into various locations such as schools, old people's homes and day centres. This work, de Wit notes, was carried on until the mid-1980s, when there was a change in the course structure at Dartington and student placements in Rotherhithe ended fairly abruptly. Some people from Dartington who had been involved in the programme did stay in or return to London, continuing some links with *the community*. One such person was David Slater, who set up 'New Moves' (later to become Entelechy) in the late 1980s. Entelechy concentrated most of its work on people with learning disabilities and profound disabilities, although other occasional projects involved different groups such as older people and school children. David Slater told me that he had been working in the area of south-east London since 1978, and currently lived in the locality with his wife and family. I asked him about his work with 'marginalised groups' and what had brought him to this:

It was finding people to work with, and in a sense the easiest people to work with were people in marginalised groups because they were in day centres or social service centres ... so if you were based in the community it was relatively easy to pick up marginalised groups ... [*they*] were in fact shepherded to us.

This would suggest it was an element of chance which brought this kind of work to people with learning disabilities. The fact that they were 'available', 'easy targets' on whom to try out new ideas, already neatly separated out from mainstream society in day centres and institutions, seems a rather dubious reason for their selection. However, he justified this decision by stating that he wanted to:

Work with a part of the population that had been highly excluded by the policies that placed people out of sight in long stay institutions ... at a time when people were being moved back into 'communities', and so we were looking at meeting, connecting with people in that group, listening to them, seeing what their interests might be in the arts and then looking at ways in which the arts could help them arrive back, or arrive in, the communities to which they had now been moved.

During my research, it became evident that New Moves/Entelechy was intimately involved in the process of moving people with learning disabilities from long-stay institutions (predominantly Darenth Park Hospital) into *the community*. Much of the company's funding during this transitional period (late 1980s-early 1990s) came from services that were engaged in this process, as David Slater explained:

We had a contract ... the services which we had to 'deliver' were based on that group of people moving back into the community and that brought us into contact with staff support teams, the agencies that were managing the process of transition ... so economically it underpinned everything we did and it brought us into quite close contact with the philosophies of learning disability services at that time, which were, compared to a lot of other operating texts ... seen to be quite radical.

When questioned as to how he thought Entelechy actually helps to 'integrate' people with learning disabilities into *the community*, or enhance their status in line with *normalisation* rhetoric, he replied:

On occasions, the work does enable people to be *recognised* or listened to or acknowledged ... that may be for just half a day, and then it's as if nothing has happened ... it's almost like marks on the sand where the tide comes in and everything is washed out and you have to start again. I think that for small moments of time, maybe even for specific projects lasting about 12 weeks, there have been shifts in perception or ideas ... I've no idea whether in ten years time it will make any long term change at all.

David, therefore, did not suggest that his company's work caused revolutionary or radical large-scale transformations in the way people with learning disabilities are 'recognised' or treated by mainstream society. Instead, Entelechy's practice mainly operated at a very subtle and small-scale level, which, in its impact on individuals' lives, may cumulatively produce radical effects. David illustrated this process of changing people's perceptions by referring to a project conducted by Entelechy a few years previously, which aimed to be an integrated performative event involving diverse people (with and without disabilities) living in and around Rotherhithe:

A couple of years ago we did a show, and there was a woman in the company who had quite profound disabilities ... she couldn't see, she couldn't hear, she moved in a way that appeared to be very different ... she had a pronounced stoop, and some local children in the show found it extraordinarily difficult working with somebody with whom they didn't know how to communicate ... her face looked very different ... It was interesting that the children's parents, who were people that I'd worked with 15 or 20 years ago ... or perhaps they were relatives, aunts or whatever ... were taking a lot of time in helping this new generation with the questions and difficulties they themselves had had previously. So maybe something happens in a small way ... when it happens it happens, and sometimes it leaves traces or trails behind ... I think to say anymore would be presumptuous.

Much of Entelechy's work was evidently based on the assumption that it is possible to build *community*, and that despite its location being in an area of social deprivation and subject to recent changes in population and environment (that is, the influx of 'yuppies' due to the redevelopment of Docklands), there is still a strong feeling of 'community spirit' in this area of south-east London. When asked about his perceptions of this *community*, David replied:

I think there are lines that connect people ... a couple of weeks ago I got really excited because somebody who runs an older people's theatre group said, 'oh, there's a man who has just played the saw in the session and it was wonderful ... and he's a support worker'. A couple of weeks later I happened to speak to a composer that we work with, Charles Hayward, and I said 'we've made a discovery ... we've found a saw

player', and he said 'oh yes, you mean so and so' ... He already knew him ... there are trails and lines that sometimes you discover or stumble upon. So there are invisible lines and networks of people, and if that is part of what a community is then yes, there is a community here ... the Dockland community ... we have worked with two or three generations of families and maybe that's part of community ... **there is a lot of it about but sometimes you can't see it.** (My emphasis).

However, David was more sceptical about *the community* which is supposed to exist to enable Community Care to take place, saying:

There is no (*community*) ... you have to treat with wry amusement that the community that people are being moved into exists ... or the way that professionals seem to talk about it theoretically. No, that doesn't exist at all. I think you have to discover it, or uncover it, or help it form for a few moments ... but if you do that then it could collapse again in two or three months or weeks or days.

Statements made by various members of Entelechy over the course of my fieldwork seemed to indicate that at some level, they believed that there was such a thing as a *community* in the area in which they operate, although they were reluctant to define it.

Rebecca Swift, the combined arts coordinator, felt that 'integration' often happened spontaneously: 'We've got the market outside. All the market stall holders know our members.' David, obviously influenced by his experience at Dartington, referred to *the local community* as having a history, to people being 'wholly alive and present to one another, and the possibilities of each other'. Many elderly people with whom he had worked had recounted moments of 'street life' and spontaneous parties in the area. He said that these collective memories have been somewhat derogatively referred to as 'fake lore', but that he has heard them so many times that he believed it was not a myth, and there existed a 'spontaneous, coincidental sharing of energy'. It was this type of 'communitas' which he wanted to recreate.

ix) Entelechy: Working at the Cross-Roads Between Social Policy and ‘Culture’

‘There is an attitude that they are fed and have a roof over their head, so what else matters?’ This comment, made by a social services employee attending a training workshop held by Entelechy, illustrates how such ‘cultural’ work is often seen as non-essential in the lives of people with learning disabilities. In many respects (particularly in regard to how it was funded by local authorities) Entelechy’s work was classed as a ‘leisure’ service, which, in the poorly funded world of social care, attracts little money. Within statutory services, what could be loosely termed as ‘cultural’ activities are not given primacy either at a financial or temporal level. It was frequently voiced by social care and health employees during workshops held by Entelechy that ‘the arts’ are not taken very seriously by service managers. However, as the data in this thesis will show, many of the activities which Entelechy organised helped people with learning disabilities to participate in the social world at a very basic and essential level, assisting in reinforcing facets which make up what it is to be a person in Western society, and which are normally taken for granted.

One question, which Entelechy explicitly set out to answer was ‘how can people with learning disabilities contribute to the cultural lives of their communities?’ The answer to this question will be explored throughout the rest of this thesis, with reference to Entelechy’s various projects entailing creative activity. The influence of their Dartington training, and that of the ‘community arts’ movement generally, could be clearly seen in much of their work, which intended to fuse ‘the arts’ and ‘social action’. When asked how Dartington had influenced his work with Entelechy, David replied: ‘it

was a very open ended training that really looked at multiple sites and sources for the theatre ... it assisted the seeking out of how theatre could emerge and connect with a different group of people in different places ... it immediately took one outside of conventional theatre sites'. Rebecca Swift, who had trained later than David and came to RTW on placement from Dartington in the early 1980s, said: 'Dartington ... was about narrowing the gap between the professional mainstream theatre and the lay practitioner, or the community if you like, but it's not community theatre. It was trying to dismantle that too, so that communities own their own theatre as first class citizens'. In response to their questioning of how people with learning disabilities are cared for in the *community*, Entelechy set up a series of workshops explicitly to address this issue.

Entelechy acknowledged that some professionals working in health and social care wished to challenge and change the way people with learning disabilities are cared for, and therefore set about creating an arena for dialogue. Over a period of almost two years, between the Autumn of 1997 and the Spring of 1999, Entelechy ran three workshops entitled 'Between Two Worlds'⁶⁴, which sought to bring together a wide spectrum of participants who worked with people with learning disabilities (with an emphasis on additional sensory disabilities). These included social services workers, day centre managers and workers, residential services workers, voluntary sector workers and arts practitioners. These workshops were intended to open up debate about the issues involved in *community care* and *the arts*, as well as to share practice, and aimed to address the following:

⁶⁴ The first workshop was held at Greenwich Dance Agency in December 1997, with the subsequent two being held at the Royal Festival Hall, on the South Bank of the Thames, in a donated space, in March 1998 and March 1999.

The structures and strategies needed to establish creative community based leisure services for adults who have a learning disability and a physical disability. Training will support staff teams to initiate:

- Cross sector developments, initiating joint working between local statutory sector agencies and voluntary sector organisations.
- Multi-disciplinary working bringing together skills and expertise of physiotherapists, health support workers, dance artists, local volunteers, day service officers and other interested participant
- Creation of funding and resourcing alliances to support small-scale but significant local initiatives.

(Extract from Entelechy leaflet)

I attended all three of these workshops (as a participant observer), which were held several months apart and lasted over a period of several consecutive days. The arts training involved in these events, in particular music and movement, are explored further in chapter 5. In all of the 'Between Two Worlds' workshops, David Slater contextualised the work of Entelechy within the wider social policy of 'community care'. He expressed the belief that people who worked with the disabled were existing within a contract-based culture, which needed to shift towards collaboration and partnership, involving *communities*, resources and development. The participants in the workshops pointed out barriers in the areas where they worked which hindered achieving the aims of 'integration' and 'cultural recognition' for people with learning disabilities. A common theme for many of the participants was a prohibitive geographical location which accentuated social isolation and the marginality of people with learning disabilities. For example, one woman said that the day centre in which she worked was located 'outside' of *the community*: 'We're in the middle of factories.' Such a location policy reflects the general attitude that such facilities are not welcome in residential areas. Another worker pointed out that her service was located in a remote rural area, where there was high unemployment and little social integration generally. Even when services were located in *the community*, it was apparent in some cases that they were not recognisable. For example, one day centre worker said that his

centre was a 'closed shop ... we are invisible. We don't have names on our van, there is no sign on the gate'. Others stated that 'integration' existed only at a contractual level, e.g. 'special schools etc. pay to come and use our sensory room'. The presumed 'vulnerability' of people with learning disabilities made it difficult for some services to invite *the community* into their day centres, as they would not necessarily have been vetted by police checks, and therefore posed a potential risk to the 'clients'. This isolation was reinforced by the lack of interest on behalf of *the community* in the day centres. One participant said, 'We don't invite people in from the local community ... we're forced to go out into the community.' The underlying idea of community care, that *communities* are open to other 'cultures' which can be inserted harmoniously at the will of social planners, is a curious one. 'Racial' and religious tensions in Britain's inner-cities attest that this is rarely the case. Why then, should the situation be any different for disabled people? It is true that many people with learning disabilities were never institutionalised, and remained in their *communities* of origin, but this does not mean that they were necessarily accepted or attributed equal status. To believe that a *community* will embrace the 'culture' of a marginalised group, who stand out behaviourally and sometimes physically, unfortunately seems fairly far-fetched.

The work of Entelechy is inevitably caught up in the conflicts and contradictions that social policies evoke. In many ways, it seeks to be a 'thorn in the side' of the establishment, providing alternative visions of how people with disabilities should be treated. From a humanitarian point of view, the underlying belief exists that 'community care' is a better option for people with learning disabilities than their prior existence in

large institutions, riddled as they were with tales of neglect and abuse. But, in supporting ‘community care’ in its present form, Entelechy were implicitly condoning free-market Welfarism, where ‘packages of care’ have to be ‘purchased’, and, inevitably, not everyone’s needs are met or are adequately provided for. This runs against their broadly socialist and utopian philosophy, and their position as ‘cultural advocates’ for this marginalised population. State-sponsored ideologies such as *normalisation* have been incorporated, at times reluctantly, in Entelechy’s practice. Entelechy’s views are sometimes solicited by statutory services, reflecting a recent wider trend to invite and incorporate ‘alternative’ and often formerly oppositional groups, working at the margins, to comment on and perhaps influence their practice. This could, however, be seen as an attempt to control potentially damaging and subversive critiques through a form of ‘colonial’ incorporation. There is, however, some potential for ‘radical’ arts companies to inculcate change, even if it is on a very minor and localised level. In the current economic and political climate, where funding is extremely scarce, perhaps the most effective way is through outward compliance, but applying covert internal sabotage, stimulating fleeting visions of other potential social orders. Obviously, an ambiguity exists, but there was a genuine desire to construct a practice out of the best of all possible worlds, even if this meant some political compromise. It is these ambiguities, and arising from these, innovations and new methods of working in the fields of performance and community relations with people with learning disabilities that I seek to explore in the following chapters.

Chapter Four

Transformations: Disability, 'Art' and 'Life'

Performances – whether ritual or dramatic – create and make present realities vivid enough to beguile, amuse or terrify. They alter moods, attitudes, social states and states of mind.

Schieffelin 1996:59

i) Introduction

In this chapter 'the arts', in particular 'performance', are examined in relation to people who have learning disabilities, incorporating ideas from anthropology and performance studies. Several of Entelechy's performance projects or 'happenings' are explored, leading the way to an opening up of debate around the issues of 'intent' and 'choice' in 'performance'. The traditional distinction between the two types of performance analysed in social science, 'the aesthetic' and 'the quotidian', is examined and it is suggested that Entelechy's work attempts to fuse the division between them. Entelechy did not concentrate on 'disability arts' in an exclusive way, but covered several areas of cultural activity. Able bodied people were heavily involved, so their work could also be seen as 'cultural intervention'. Additionally, Entelechy's facilitators were quite explicit that they did not view their work as 'therapy'. This does not, however, preclude it from being transformative, especially as the expressive and emotive dimension of creative activity was emphasised. Within Entelechy's body of work, people with learning disabilities were attributed with the capability of being able to express emotion, and their communicative attempts were given value and intent.

The idea of 'relatedness' or *communitas* mentioned in the previous chapter is shown to be central to Entelechy's practice. In the examples provided below, Entelechy's projects

or 'happenings' attempted to create a meeting ground and dialogue between people of widely differing abilities. There exists no culturally recognised way of communication between people without disabilities and people with learning disabilities and/or profound and multiple disabilities, so Entelechy set about the process of creating such a dialogue, frequently through non-verbal means, utilising visual arts, dance and drama.

ii) 'Art' and 'Life'

Much of the rhetoric surrounding current approaches to how the lives of people with learning disabilities should be lived in the 'rational community' concerns 'ordinariness' and 'the everyday'. This needs to be compared to Entelechy's assertion that people with learning disabilities express 'intention' in their actions as social persons - even the quotidian is meaningful and can be incorporated into an aesthetic. If Hughes' (2000) proposition that contemporary Western life is aestheticized is accepted, this has consequences for people with learning disabilities, who are often perceived as outside mainstream, 'normal' aesthetics. Can creative activity ('the arts') be used as a tool in social change, as direct intervention, while still remaining true to the quotidian? The theorist and literary critic, Raymond Williams, has suggested that this is possible: 'Here, undoubtedly, is the point of growth of any drama of our century: to go where reality is being formed, at work, in the streets, in assemblies, and to engage at those points with the human needs to which the actions relate' (Williams 1991: 171).

Performance work with and by people with profound and multiple disabilities inevitably raises questions of intent, consent, power and exploitation. Entelechy was trying to move away from therapeutic paradigms (which they felt were constraining), towards

cultural and creative expression, shifting the aesthetics of performance towards unpredictability, chance, chaos, and, perhaps, the oxymoron of ‘controlled anarchy’⁶⁵. This type of work has taken place in other areas of *avant garde* performance for most of the twentieth century, for example in the work of Artaud, Grotowski, the Living Theater (USA) and The People Show (UK). The transposition of this kind of thinking to the area of learning disability arts, where there is often no way of knowing the intent of the ‘performers’, is indeed radical but raises difficult questions. For example, by interpreting such activity as ‘art’, is the experience devalued or even parodied? Is ‘power’ (whatever this is understood to mean) taken away when activities are ‘framed as’ performance? These questions remain to be answered. However, much of the lives of people with profound and multiple disabilities involves passivity. One way out of such passivity is, perhaps, their involvement in the *avant garde*, which allows them to be at the forefront of negotiating new performance aesthetics and ways of communicating lived experience, and bringing to light the fact that we all experience the world as intersubjective and intercorporeal beings.

The anthropologist Schieffelin has asserted that social science has used the concept of ‘performance’ in roughly two ways. Firstly, as ‘symbolic’ or ‘aesthetic’ activity, ‘intentional’ action such as ritual and theatre, which is ‘marked and set off from ordinary activities’ (1998:194). This traditionally involves a performer/audience split, whereby such performances: ‘aim to evoke an imaginative reality or an intensification of experience among the spectators, and bring about an altered awareness of their

⁶⁵ In the sense that certain ‘deviant’ acts were prohibited in the workshops, such as open masturbation, and violence towards self or others.

situation and/or a sense of emotional release' (ibid:195). Secondly, it has been taken to mean 'performativity' itself: 'the expressive processes of strategic impression management and structured improvisation through which human beings normally articulate their purposes, situations and relationships in everyday social life' (Schiefflin 1998:195). Both of these perspectives, Schieffelin suggests, draw their terminology from Western theatrical performance. He asserts that 'there is something fundamentally performative about human being-in-the-world. As Goffman has suggested (1959), human intentionality, culture and social reality are fundamentally articulated in the world through performative activity' (Schiefflin 1998:195). What, then, occurs when people with learning disabilities, who are seen as less culturally embedded than other social actors, engage in explicit performances?

As an externally imposed cultural and social grouping (as they rarely identify *themselves* as 'incompetent') people with learning disabilities present interesting issues for anthropological enquiry, particularly in relation to 'performance'. They are so named because they have difficulty understanding the rules of interaction, and what Goffman (1963b) calls the 'social order' is constantly reinforced by their non-disabled peers. As the anthropologist, Edgerton (1985), pointed out, people with severe learning disabilities are often exempted from responsibility in following their culture's rules. However, disability is not excluded from Western performance aesthetics, as it has frequently arisen in metaphorical form as 'tragedy', a metanarrative within which the experiences of people with learning disabilities need to be understood. It is suggested that the tragic device within this tradition acts to restrict the roles of performers who

have disabilities, and frequently confines such work to therapeutic paradigms or relegates it to the art of 'the Other'.

iii)Tragedy

In order to understand the issues involved in performance work with people who have learning disabilities, it is important to look first at the idea of tragedy and the representation of disability, leading to an exposition of the cathartic function in such work. The Western theatre tradition stretches back to the ancient Greeks, with Aristotle's assertion in his *Poetics* that 'poetry' and 'politics' are separate. However, the theatre practitioner and social activist Boal, has argued that Aristotle was setting out the 'first, extremely powerful poetic-political system for intimidation of the spectator, for elimination of the "bad" or illegal tendencies of the audience' (Boal 1979:xi). He asserts that through the dramatic device of tragedy, the political status quo is upheld. This is because:

Tragedy imitates the actions of man's rational soul, his passions turned into habits, in his search for happiness, which consists in virtuous behaviour, remote from the extremes, whose supreme good is justice and whose maximum expression is the constitution. In the final analysis, happiness consists in obeying the laws. This is Aristotle's message, clearly spelled out.
Boal 1979:23-24

Boal (who is concerned with all forms of oppression, and not specifically with disability) suggests that repression is not the *only* function of Greek tragedy, and other aesthetic concerns are involved. However, the repressive function is seen by him to be the most important, and this is because 'according to Aristotle, the principle aim of tragedy is to provoke catharsis' (Boal 1979:25). Tragedy, Boal asserts, provokes the emotions of pity and fear in the spectators as they identify with tragic flaws in the characters: 'Clearly, the fundamental empathic emotions of pity and fear are evoked on

the basis of an ethos which reveals good traits (hence pity for the character's destruction) and one bad trait, hamartia (hence fear, because we also possess it)' (Boal 1979:35). Catharsis, that is purgation of the hamartia (tragic flaw), occurs in the spectator, in a number of stages. First there is 'Stimulation of the hamartia; the character follows an ascending path toward happiness, accompanied empathically by the spectator' (ibid:37). He (sic) then passes through a recognition of his error (anagnorisis), which is followed by catastrophe. He suffers the consequences of his error and ends with '*Catharsis*: The spectator, terrified by the spectacle of the catastrophe, is purified of his hamartia' (Boal 1979:37).

The concept of 'tragedy' in performance often takes on an embodied form, that is, as a disability. Hevey, a disabled artist and theorist, asserts that if the flaw in the character in tragic theatre (e.g. Richard III; Oedipus) is the 'site of the social, ethical, legal and moral order of the day and the price of transgressing these codes, then clearly disablement becomes the highest (that is the lowest) form of transgression' (Hevey 1992:108). Tragic theatre, he suggests, is essentially similar to tragic charity advertising, the tragic medical model of disability and the tragic portrayal of disabled people in theatre, television, films etc. He explains this through the example of the Oedipus story, asserting that:

The price of his transgressions, the utmost flaw, in this story (and in most tragic theatre), is positioned on and within the impairment. Oedipus blinds himself to make physical that which was fate. Oedipus, in effect, carried onto his body the order - that is, the rules of the social organisation - and the orders - their enforcement - of the Greek State. He paid for his transgressions (in this case, love of the mother, or patriarchy) by becoming disabled.

Hevey 1991:25

Hevey is suggesting therefore, that 'fate must be made physical on the body' (ibid.)

What he terms the 'tragedy principle', which occurs in multiple forms of 'tragic' media

representation, uses impairment as a metaphor for a socially unacceptable person. A new aesthetic, Hevey suggests, is needed. All art involves emotional catharsis, he argues, but it needs to be established which emotion is being catharted, and in the case of tragedy, catharsis is only achieved at the expense of disabled people. He makes a distinction between 'impairment' and 'disability', and suggests that there needs to be shifts in representation in order to decrease the oppression of disabled people.

However, Hevey (1993) argues that to replace 'negative' disability imagery with 'positive' imagery does not constitute a cultural or political advance. This is because, following his reasoning, unreconstructed 'positive' images could be seen as repressing the tragedy principle, rather than liberating disabled people. Instead, he demands that creativity should be political, incorporating the artist's relationship to the 'disability struggle' and how this is reflected in their selfhood. Radical theatre, Hevey (1992) asserts, should examine a theory of the subject; a theory of the tragedy principle (and routes beyond it); and a theory of the process of representational production. He outlines a history of 'radical theatre' drawing on the work of Ionesco, Boal and Brecht. Radical theatre, he asserts, challenges and deconstructs 'tragedy' in the laboratory space between viewer and viewed, audience and performer. In a later article Hevey outlines a threefold cultural task for disabled artists and cultural workers, namely:

First, how to 'reclaim' impairment away from a social flaw. Secondly, how to shift disability representation off from the body and into the interface between people with impairments and socially disabling conditions and, thirdly, how to create aesthetic forms which are seen to deal with this successfully (i.e. which can be internalised by disabled people in struggle).

Hevey 1993:426

Hevey's arguments (1993) are very much in line with earlier 'social models' of disability, asking for a 'de-biologisation' of disability. At the same time, he claims that

disability arts is the only area of the arts to have exploited new technology to its full potential. This is evidently not the case, as can be illustrated by the plethora of performance work, specifically in the 1990s, involving people of all abilities dealing with this subject. Fulcher (1996) criticises Hevey's simplistic dualistic concept of 'the body' and 'society', which overlooks the fact that (from a Foucauldian viewpoint) everyone is 'governed by the coercion and production of docile bodies. This occurs both in the "economic" and "cultural" spheres, and more broadly: the social enters into, is constituted, in part, by the regulation of the body.' (Fulcher 1996:178). Hevey's argument that disability arts represent post-tragedy disability culture, centres around the separation of the terms 'impairment' and 'disability', and their non-exclusive connection to 'the body'. This, he asserts, has left a 'cultural vacuum' that only disability arts can fill. This rather essentialist position is in many respects teleological: if the focus has moved from 'the body' how is it that those with a specific kind of body (the disabled) define the movement? In many ways, as Fulcher has pointed out, Hevey's position is part of a broader tradition concerned with the revolutionary potential of art, claiming:

Culture as not secondary to some more basic phenomenon but as having materialist realities and transformative possibilities. This is to argue ... that artistic practices with a political poetic (itself a complex idea and practice - not to be identified as necessarily a characteristic of the artistic products of disabled people) raise issues of awareness, consciousness, constituency and therefore political mobilisation.

Fulcher 1996: 179

Some attempts have been made to render the division between disabled/non-disabled art obsolete. An example of this is DV8's recent physical theatre production, *Can we afford this: the cost of living*, which was not so much about 'integration' or denial of difference, but instead an acknowledgement of the diversities, strengths and fragilities of the human form. The production, in what appeared to be a parody of 'political

correctness', included performers who had physical disabilities, those who were HIV positive, ex-drug addicts, and those who were very fat or very thin⁶⁶.

This type of performance has the potential to be very provocative. This is because it sets out to question the embodied 'tragedy' of all our lives, not just those categorised as 'disabled', and in some respects make this 'deviancy' normative. This is very challenging, as it seeks to deconstruct the binary upon which difference is based, that is, abnormal/normal, disabled/non-disabled, deviant/mainstream. As Hughes points out: 'The mainstream cannot identify itself or confirm the exalted - at worst 'normal' - nature of its existence without reference to the margin' (Hughes 2000: 558). By attributing such insights entirely to 'disability arts', as is suggested by Hevey, such binaries are overlooked and normative structures reinforced. However, an impasse is reached if such theatre is seen simply as 'integrated', 'inclusive', denying difference and individual experiences of suffering.

The ambiguous status of people with learning disabilities, explored in earlier chapters, evidently has a bearing on how they are perceived as performers. This is a particularly pertinent issue when the people concerned have been classified as having 'profound and multiple disabilities', in that they do not appear to have many of the attributes that supposedly make up a competent social actor. The fact that they are often very dependent on others for their care makes it very difficult for the general population to see such people as independent 'actors', capable of performing in their own right. If

⁶⁶ In many respects, this production was a continuation of themes explored in previous DV8 productions such as *Bound to Please* (1997), which used 'dance metaphorically to question about conformity, intolerance, escapism and denial' (Hutera 1997: 14)

this group of people participate in the performing arts, can it, indeed, really be called a 'performance' when the 'performers' often aren't even necessarily aware that they are 'performing'? This point has been touched on by the anthropologist and theatre practitioner, Richard Schechner, who asserts that it is important to discern whether:

A performance generates its own frame, that is, is reflexive (self-conscious, conscious of its audience, the audience conscious of the performer being conscious of being a performer etc.); or whether the frame is imposed from the outside, as when TV crews arrive at the scene of a 'tragedy'.

Schechner 1990:28

An elephant at a circus, a 'crazy' woman in a public place talking to herself, or people involved in real-life tragedies shown on television, are, according to Schechner 'framed-as' performances. Schechner also includes in this category, the performance by Richard Wilson and Christopher Knowles in the 1970s, entitled *Dialog Curious George*. Christopher Knowles had a learning disability, and 'performed' on stage with Wilson, by just 'being himself':

Wilson contexted his interactions with Knowles as a performance for the public who paid fancy prices to witness and admire it. Sometimes Knowles' responses - his way of re-telling a children's story, and Wilson's questions to Knowles, were very funny, wise, ironic, appropriate: one of those Simpleton Saints. Saint or not, Knowles was an elephant bowing at the circus - whatever his remarks meant to members of the audience they meant, or were, something else to Knowles. Because Knowles couldn't lie, he couldn't be an actor - he could only be *situated and displayed as if he were an actor* inside Wilson's show.

Schechner 1990:38 (original emphasis)

This position could be taken to imply that most performance work involving people with learning disabilities is a kind of pejorative voyeurism: 'they' are not in on the joke. In *Dialog Curious George* there was a traditional audience/performer divide, with connotations of a 'freak show': the disabled person was on display. The work of Entelechy differed from *Dialog Curious George* in that they attempted to get within the traditional performance aesthetic and change it to make it more inclusive, although this

has sometimes met with varying success. Additionally, in most of the ‘performances’ described in this chapter there was no verbal dialogue. Entelechy’s groups took place most often in workshops and ‘happenings’ where there was a much less clear audience/performer divide, boundaries were blurred, ‘the gaze’ was not necessarily one way, and other senses rather than the purely visual were explored.

The audience/performer dialectic upon which ‘tragedy’ is based has been radically questioned by some arts companies working with people with learning disabilities. As

Kuppers suggests:

The works of companies with disabled performers ... can enhance our understanding of the diversity of embodiment. They can do this not just by ‘adding difference’ to the norm, but by nourishing developments in dance’s communication with bodies, by reinventing centres, normalities, ways of seeing and doing, and by keeping dance alive.

Kuppers 2000: 129

Kuppers refers to two performances by groups with disabled members which very consciously set out to disrupt traditional audience/performer relations, through ‘framing’:

The frame of dancetheatre lifts bodies, actions and movements out of their everyday meaning and allows us to see them differently. By doing this, performers can show the constructed nature of the everyday, the assumptions that the spectator brings to an image, a performance.

Kuppers 2000: 126

The first performance she refers to involved Magpie, a company with learning disabled dancers, and Retina Dance Company at the Blitz ’97 festival in London. The performance was held at the South Bank centre in London, inviting the audience to view them through glass windows: ‘The more isolated and uncomfortable audience members felt, the better. After all, as both companies point out, it’s only a reflection of the way those with learning disabilities frequently feel as outsiders looking into society’

(Cowl, 1997:16, quoted in Kuppers 2000: 127). This physical framing, Kuppers asserts, reflects the conceptual framing of people with learning disabilities in our society, pointing to the social dimension of disability: ‘the creation of disability in the encounter between people, their value systems, and the expression of these values in the institutions that we live with’ (ibid.).

The second performance to which Kuppers refers, involved the Austrian performance company, Bilderwerfer, which was composed of people with varying abilities, including people with physical and/or learning disabilities. The performance, entitled *Einblicke* was held in 1995, behind a glass window shopfront, with the audience sitting or passing by, aiming to disrupt fixed ideas about disability and dance:

Texts and music were piped to the audience through loudspeakers, the ‘natural’ presence of the body in dance was disrupted through these distancing mechanisms. The choreography worked with notions of privacy and a refusal to show. In one part of the performance, dancer Elisabeth Loffler created elaborate, fluid arrangements in space with her body on the floor, her wheelchair and her crutches juxtaposing and aligning themselves, emphasising shapes and pathways.

Kuppers 2000:127

Kuppers asserts that there was no clear narrative emanating from the piece for the audience, suggesting that Loffler ‘denied any emotional reading of her movement study’ (ibid.), through refusing to engage with the audience. This, Kuppers argues, led to a presentation of the disabled body as ‘different, but not yet categorized’ (ibid.), thus complicating the interaction between audience and performer. The aesthetic strategies in both performances aimed to force the spectators to become aware of themselves.

Entelechy’s work, which is discussed below, also aimed to be disruptive of audience/performer dialectics, most clearly seen in their workshops and ‘happenings’

where the 'audience function' was displaced or even eliminated in order to produce a new aesthetic which was inclusive and expressive of all of the participants various abilities. The efficacy of such 'performance' work was difficult to discern. The potential for 'transformation' among those who took part is discussed later in the chapter.

iv) Performance Art: an Arena for the Exploration of Possibilities.

Much of Entelechy's work with people with learning disabilities needs to be understood within the context of the genre of 'performance art', rather than 'theatre'. Their work sometimes developed what could loosely be called 'post-modern rituals', focusing on the personhood of people with learning disabilities. Such self-conscious, 'made-up', fragmented ritual, such as the 'Incredible Journeys' project described below, is, according to the anthropologist, Gerholm (1988), a common feature of the post-modern world. He argues that rituals are not just expressive of abstract ideas, but are processes which have effects on the world, that is, they are performances.

Carlson has defined 'performance art' as requiring 'the physical presence of trained or skilled human beings whose demonstration of their skills is the performance' (1996:3). Performance art involving people with learning disabilities could, therefore, be seen as a contradiction in terms, as the individuals so defined are marked out as less 'skilled' than the average member of society. Carlson charts the history of modern performance art, which he asserts is often taken as 'essentially the history of twentieth-century avant-garde theatre' (ibid:79). He proposes a wider historical survey of performance, including court jesters, rope-dancers and cabaret. The roots of modern performance art

can be found in the early years of last century in Europe in the futurist movement and Dadaism, which were interested in movement and change and a transfer of emphasis in the artistic process from product to process:

Both dada and surrealism were interested in spontaneous creative activity. Some of this involved pure chance, such as Hans Arp creating collages by allowing scraps of paper to fall randomly on the floor, Tzara creating poems by pulling words from a hat, or more theatrically, dada performances attempt to stimulate and incorporate audience reaction. There was also, however, an interest in tapping and expressing the unconscious, what Andre Breton called "pure psychic automatism" ...

Carlson 1996:91

Similarly, Entelechy aimed to focus more on process than product⁶⁷, as well as emphasising the 'unconscious' and 'spontaneity', in their work with people who had learning disabilities, moving towards different aesthetic sensibilities. This point is returned to later. Artaud had a great impact on experimental theatre and performance art when his work was rediscovered in the 1960s and 1970s. Entelechy's work could be seen to be influenced by him, specifically his insistence on a change of emphasis from spoken language towards direct 'physical and objective' action. Much of Entelechy's work could also be seen to be attempting what Artaud has termed 'total theatre', involving embodied physical action and the mixed media of music, lights and objects, incorporating random and incidental noises from the performers, such as groans and screams. He had argued that theatre had lost touch with 'real' life and human experience, and that it should be more than just entertainment, and should be genuine action with real effects upon the real world.

⁶⁷ Perhaps this was because the 'product' was difficult to assess in terms of mainstream aesthetics. Although Entelechy tried to create alternative aesthetics, mainstream aesthetics were the terms through which they usually had to explain their work in order to get funding or recognition.

Artaud's theatre drew on Freudian theory, suggesting that society's ills stemmed from repressed desires in the individual. Post-Freudian theatre, according to Wright, 'dispenses with any notion of the arts as safety valve for repressed wishes. Such wishes are rather to be seen as a revolt against oppressive systems of all kinds' (1996:177). Entelechy's 'rituals' and 'happenings', which incorporated critiques from post-modernism, took Artaud a step further, in a similar way to that described below:

... by making speech compete with other elements on the stage, such as music, sound effects, gestures, sets, props, lighting, mime, mask. The most significant features of performance are the disturbance of the boundaries between artist and spectator, spectator and art "object", art "object" and artist. This form of subversively implicating the audience with what is happening on stage and vice versa has become the basic structure of post-modern performance.

E.Wright 1996:177

Much performance art activity in the 1970s was situated in America, and the San Francisco Bay area became a centre for 'life art' which involved the 'framing, intensifying, or ostending everyday activities' (Carlson 1996: 97). Activities such as sleeping, eating or just being still in unusual places were 'framed' as acts of performance. Carlson identifies two strands of performance art which developed in the 1970s, one of which concentrated on the single performer and his or her body, making use of everyday actions and materials. This tradition has been continued in the work of contemporary performance artists, for example Bob Flanagan, who had cystic fibrosis, expressed his experiences of pain and suffering through performances involving sado-masochism. The second strand of performance art, which did not become identified until the 1980s, is:

Devoted to the display of non-literary aural and visual images, often involving spectacle, technology and mixed media. Both approaches were often usually undertaken outside traditional theatre spaces ... (and) came to be known as "site specific" or "environmental"

Carlson 1996:104 -5

Most of Entelechy's one-off performance events or happenings, which are described below, could also be described as site specific, for example they took place in parks, or in community centres, away from traditional sites for aesthetic activity.

Work which went against the verbal and narrative traditions of mainstream theatre was termed 'the theatre of mixed means', by Richard Kostelanetz in 1968, emphasising instead:

Sound and light, objects and scenery, and/or the movement of people and props, often in addition to the newer technologies of films, recorded tape, amplification systems, radio, and closed-circuit television ... works that rejected traditional plot, character, setting, and especially language, to emphasize process, perception, the manipulation of time and space, and the tableau to create a new stage language, a visual grammar 'written' in sophisticated perceptual codes.

Carlson 1996:105

Such a genre, as I illustrate in my ethnography, is ideally suited to work with people who have profound and multiple disabilities, who do not communicate through verbal means.

It can be seen that the work of Entelechy incorporated the influences of the 1960s, 1970s and 1980s. Its work with people with multiple and profound disabilities focused on the body and movement, rejecting discursive language, whereas groups such as 'Weaver' (examined in chapter 6) and 'Through the Door'⁶⁸ incorporated narrative, albeit in a post-modern way; for example, the performance of non-sequential narratives such as those produced by people with autism.

⁶⁸ 'Through the Door' theatre company was a group run by the Advocacy worker for Entelechy, Pam Martin. It was somewhat independent of Entelechy, as it had its own management committee, made up of people with learning disabilities.

In order to elucidate some of the ideas and problems which occur in performance work with people who have learning disabilities, ethnographic data from a few of Entelechy's projects are examined, followed by a theoretical exploration of issues raised.

v) Entelechy's 'Happenings'

Much of Entelechy's work had the intention of being seen as 'happenings', in the form of one-off performances and projects. These were in addition to the weekly workshops, and were funded by different bodies through individual grants. Several of these 'happenings' occurred during the course of my fieldwork, and others were recounted to me by members of Entelechy. In the history of 'performance art' Kaprow has been accredited with the first 'happening', taking place in 1959, in which: 'Audiences ... were seated in three different rooms where they witnessed six fragmented events, performed simultaneously in all three spaces. The events included slides, playing of musical instruments, posed scenes, the reading of fragmentary notes from placards, and artists painting on canvas walls' (Carlson 1996:96). 'Happenings' were intended to differ from theatre pieces and performances in that they were spontaneous events. Kaprow was against the theatricality that having an audience produced, and suggested the following guidelines, summarised by Carlson: 'keeping the line between art and life fluid and perhaps indistinct, seeking themes entirely outside the theatre or other arts, using several different locales and discontinuous time to avoid a sense of theatrical "occasion," performing happenings only once, and eliminating entirely the traditional, passive audience.' (Carlson 1996:97). Entelechy's 'happenings' aimed to be arenas where new ways of communicating the experiences of people with learning disabilities could be explored, and perhaps disseminated to a wider public through aesthetic means.

However, Entelechy's 'happenings', though 'framed as' spontaneous, were often tightly controlled.

a) 'Untitled' and 'Coincidences'

These two 'happenings' were based around movement 'encounters' between professional dancers, people who had profound and multiple disabilities, and some people from the local *community*. The main movement genre utilised was 'contact improvisation', which is explored in Chapter Five. What I aim to do here is to outline some of Entelechy's thinking behind such projects and interactions, and how this was reflected in the 'happenings'.

The first 'happening' which I observed was named 'Untitled', and was held in the Spring of 1997. It was funded partly with a grant from the RNIB⁶⁹, and involved physical encounters between artists, carers, and people with profound and multiple disabilities including a visual impairment. This experimental 'happening', facilitated by Rebecca Swift, occurred over a period of weeks, with the group meeting at the local arts centre. Rebecca described how she felt interacting with a woman who was blind and deaf, and whom she had never met before:

It is hard to think that anything of creative, social and artistic value might be happening when two people are sitting very still for 30 minutes, sometimes doing a hand dance with one hand and a few fingers each. Half way through the dance the participant held my hand and wrist and didn't let go for fifteen minutes. With her fingers tightly around my wrist it meant she could pick up my pulse.

(extract from Entelechy document)

⁶⁹ Royal National Institute for the Blind.

Entelechy aimed to make such encounters meaningful, even if the appearance was of 'doing nothing'. The blind and deaf woman with whom Rebecca was interacting had her actions described as 'dance', indicating Entelechy's aim of expanding aesthetics to incorporate mundane movements. Through 'framing' everyday movements as 'art', Entelechy appeared to be attributing intent and a certain degree of 'authenticity' to the actions of people with disabilities with whom they worked. David Slater argued that what was important where there was no shared spoken language or gestures was to 'just be' together. To 'just be' present in the company of another person, David suggested, was a skill that needed courage and confidence. Rebecca's moment of 'shared stillness' with the woman who had multiple disabilities evoked in Rebecca many emotions:

Moments of paranoia washed over me. I was wondering how much she would pick up from me, since holding my pulse meant she had an intimate knowledge of my state of mind, however well I could hide it on the surface.

(Extract from Entelechy document)

The intersubjective nature of Entelechy's 'encounters' with people who had profound and multiple disabilities is explored further in Chapter Five. Here it is important to point out that the Entelechy facilitators felt that they could open up pathways of communication through aesthetic means, utilising their skills as 'trained performers' to enter the world of a profoundly disabled person, and that both could learn from each other. This valuing of the actions of disabled people as 'authentic' was stated clearly by Yolande Snaithe, a choreographer employed by Entelechy in their dance and movement project/happening entitled 'Coincidences'⁷⁰:

⁷⁰'Coincidences' took place before my involvement with Entelechy. I was able to view a video which had been made of the performance, and the performance was recounted to me several times by Entelechy facilitators.

I see the experience I'm having ... as an exchange. I'm getting as much stimulation and inspiration from working with the group as they are getting from me. My experience of this project is how can we exist in the same world and each person be themselves fully ... within the group and actually break down this sense that this is a professional dancer and this is somebody who is dependent upon other people to move. To break all these roles down and for everybody in the group to put in whatever range of movement or whatever voice or music they have.

(From Entelechy document)

The 'Coincidences' project was referred to several times by Entelechy's facilitators to illustrate whether an individual exerts 'choice' in a performance. During this project, a woman who had profound learning disabilities (but who was ambulant) spent almost the whole of the performance sitting at the side of the stage area with her care worker, 'as if' a member of the audience. Near the end of the performance, of her own free will, she dashed on stage and became part of the proceedings. The Entelechy facilitators asserted that what should be concentrated upon were those few seconds in which she 'chose' to perform. Entelechy attributed this participant with intent, as they did all performers. In post-modern performance there is not a clear distinction between where everyday actions end and performance begins, and this is reflected clearly in the work of Entelechy.

b) Incredible Journeys

The Incredible Journeys project, held in Spring 1999, and designed by David Slater, set out to focus explicitly on 'transitions'. David's original aim had been to develop a project which would create social ties between local sixth formers (who did not have disabilities) and a group of their peers who had profound and multiple disabilities, using 'the arts' as an arena for such encounters. The shared 'transitional' element was to be the participant's somewhat 'liminal' status between childhood and adulthood, which

was to be reflected in the project. Questions were to be explored around the issue of 'independence' for both the disabled and able young people. Albright, writing about dance and disability, shows clearly how the transition to adulthood for people with disabilities is hampered by Western⁷¹ notions of self and autonomy:

We still believe that the primary moment of selfhood is when the child (or young adult) becomes independent from her parents or caretakers. This construction of the self as an autonomous individual has always been problematic for women and for men who are implicated in various threads of interdependence, but it is particularly so for people who need daily physical assistance with their lives.

Albright 1997:61

The Incredible Journeys project's stated intention was to bring to the surface the dilemmas that a person with multiple disabilities faces when approaching the transition to adulthood, that is, conflicting notions of independence and dependence, and how this could be metaphorically and aesthetically represented in the idea of 'journeys'. The project aimed to bring together a mixed ability group of young people, working alongside performance artists and musicians, to design a theme-based interactive environment. However, due to various reasons (which appeared to be largely to do with the timetabling of lessons and examinations), the small group of able-bodied sixth-formers who had originally been involved in the design of the project, dropped out. Funding was received (in the form of a local authority grant) for a smaller scale exploratory project, involving three young people who had both physical and learning disabilities⁷². As the ethnography will show, the project veered away from any easily identifiable connection between the actual occurrences and any 'transitions' in the participants' lives.

⁷¹ It is important to note, however, that the three disabled participants came from diverse cultural backgrounds, suggesting different notions of what it meant to be an adult.

⁷² These three young people were put forward by their carers, after Entelechy advertised (within services) for participants in the project. None of them had been involved with Entelechy previously.

Incredible Journeys, in its eventual form, was devised and performed during the Spring of 1999. The project involved:

Three young people with multiple disabilities (aged between 19 and 21); a performance artist; a DJ and visual artist; members from the Entelechy core team who were trained in performance art; a visual impairment worker; a speech therapist; care workers; an eight year old violinist; a sound recordist; family and friends who 'dropped in'; and myself.

Thus, the three young people at the focus of the project were outnumbered by various 'professionals' (artists and care workers), and a few volunteers, most of whom they had never met before their involvement in the project. The three young people with multiple disabilities came from diverse backgrounds, and included:

Ezra: a 20 year old man who was terminally ill as a result of a degenerative neurological disease, which had also made him lose his sight. Ezra was able to speak, although he was not always able to make himself understood. He was part of a large Turkish family, and was soon to undertake a journey to Turkey where he would be married.

Madeleine: a 19 year old woman from Ghana, who was visually impaired and had learning disabilities, and who had been in England for only a year. Madeleine was able to hold simple conversations.

Stephen: a 21 year old man who had a severe form of cerebral palsy. He was virtually paralysed and had learning disabilities. He was unable to speak, although he could make some vocal sounds, and was able to move his right hand only slightly. Stephen was from a white, British, south London background.

Stephen had recently moved to a supported house, away from his family. He had therefore made part of what is often seen as a key element in the transition to adulthood, although he was still extremely dependent on others for his basic care. Both Ezra and Madeleine lived with their families. This may have been due to their differing cultural backgrounds, but this was difficult to establish.

The project began in April 1999, with a meeting at a local arts centre. It was spread over several weeks, with the group meeting up on about eight separate days. Although this project ended with the making of an installation, which tried to encapsulate the creative process which had occurred over a period of time, it could be better described as a 'happening' rather than a straightforward exhibition or performance.

Material for this project was collected in several ways. There was a market next to the arts centre, which mainly catered for the large, local Afro-Caribbean community. The three disabled members of the project were taken there by the rest of the group ('supporters') to experience the sounds, smells and general ambience of this very busy venue. During their visit small items were bought, and their supporters picked up objects found at the market such as leaflets, cardboard and a discarded tie. The group returned to the arts centre, where everything that had been bought or collected was displayed on mats or pinned to the walls.

On another day a visit to Kew Gardens by minibus was undertaken by the participants in the project. It was unclear why Kew Gardens had been chosen, although one possible explanation was that it was a place which could be experienced in a multi-sensory way. The group spent some time visiting the conservatories, and later collected fallen leaves, pieces of bark and flowers. The visually impaired members of the group, Madeleine and Ezra, were guided to feel the plants and some of the sculptures, and Stephen was pushed in his wheelchair under leaves and blossoms so that they touched his skin. The whole visit was documented by photographs and a video. A dictaphone was switched

on, placed around Stephen's wrist and rested on his chest, to enable the sounds to be recorded as he went around Kew Gardens.

At a later date, the group reassembled at the arts centre for a four-day workshop to prepare the performance/installation. Rebecca attributed an innate artistic ability to everyone, and expected that they would all take part in creating an unusual indoor garden in a multi-sensory room, the aim of which was to connect memory and experience for the three young disabled people. As part of the preparations, Ezra and his supporters made leaves out of clay, and although Ezra enjoyed the feel of the clay, his 'leaves' were mainly rather random shapes. Madeleine and Stephen worked with Rebecca and Chet, a visual artist and DJ, using sound. They experimented with a keyboard and Madeleine was recorded singing and playing. A microphone was placed near Stephen's mouth, and he was encouraged to make sounds by copying Rebecca and Chet. The echoing and repetition of sounds, plus Madeleine's singing, resulted in a recording lasting several minutes, and this was later used in the installation.

A local recording studio was hired for the group. Lucy, an eight year old girl⁷³, accompanied Ezra on her violin while he sang soft, sad Turkish songs. Madeleine sang and played the drums. David Slater also played the violin, and he felt that the music became most interesting when they all worked together to produce ‘the drone’⁷⁴ quality of sound. Snippets of conversation were also interwoven with the music. At the end of the day, the sound engineer from the studio brought the master copies of the tapes that had been recorded over to the arts centre, where they were played to the group. Although not all aspects of the recording were as clear as had been hoped, Rebecca felt that the personalities of those taking part in the recording ‘had been threaded through into a tapestry of sound’.

At the next workshop, photographs of the visit to Kew and the activities at the arts centre were scanned on to a computer and reproduced as transparencies which could be projected on to the walls. Lee, a visual impairment worker, had a heat sensitive device which picked up images and made them raised and tactile. Stephen’s foot and several people’s hands, including Madeleine’s, were scanned, and these life size images were stuck on to card, cut round, and later used in the installation.

A few days later the performance/installation took place in a residents’ association hall, which Entelechy had hired, and which was based on the visits and workshops which had occurred over the previous weeks. The recreation of Kew Gardens was attempted by hanging feather boas from the ceiling, with marshmallow strawberries attached to the

⁷³ Lucy was the granddaughter of a local woman who had been involved with community arts work for many years.

⁷⁴ ‘The drone’ is described in Chapter 5.

ends to simulate the aromatic plants under which the participants had moved. Images of large Koi fish, which they had encountered at Kew, were projected onto a prepared alcove. Tape players were hidden under Astroturf, and the tapes which had been recorded during the process of the project were played.

In one section of the hall, Rebecca set up a chest of drawers. Inside each drawer she placed items which had different smells and textures, such as damp bark, feathers, cut passion fruit and earth. In the top drawer was a dictaphone playing a tape of the project participants' voices. Nearby, a television monitor and video recorder showed the tapes made at Kew. Bark was placed around the television monitor, and a wheelchair was draped with ivy.

An exhibit was made of the scanned hands, which were placed like leaves around a mechanical hand in a flowerpot. The scan of Stephen's foot was stuck on to a glass window, underneath a scan of Madeleine's hand. A transparency of Madeleine and her sister was also displayed on the window. A scan of Stephen and David, which was bordered with Astroturf to make it tactile, was stuck on to a graffitied wall outside. On the outside of the hall, Rebecca placed several photographs and scans from the computer depicting events which had taken place during the project.

Madeleine had attended the 'happening' for most of the day and had interacted with Entelechy facilitators and invited artists by singing and drumming. She listened to tape recordings and seemed to recognise and respond to the sounds and voices. A tape recording of her own voice had been placed in a bush outside, and another one was

inside the hall. Madeleine was intrigued by these tape recordings and said that listening to the two sources of sound made her feel as if she were two different people.

Stephen arrived with his care-worker at about 1pm. Rebecca attempted to involve Stephen in the performance/installation by encouraging him to use his Delta Talker (an electronic communication aid) as part of the installation. He had also brought along a remote-controlled car, which it was hoped he would move around the floor during the 'happening'. However, he was reluctant to do either of these things and remained quite passive. Stephen's mother and younger brother came and looked at the installation and photographs. Afterwards, they took Stephen away for part of the afternoon, but all three returned later.

Ezra arrived at the hall at 3pm with another young man who had learning disabilities, and their two care workers. They looked at and interacted with the exhibits. Ezra spent a long time examining the contents of the chest of drawers, and was fascinated in particular by the tape recorder. He spent a considerable time by the projections of the fish (he was able to pick out some shapes and light), and also enjoyed listening to the tape recording of his Turkish music. Although Ezra appeared to enjoy very much the period he spent at the performance/installation, it was evident to Entelechy facilitators and myself that Ezra attended this event more in the role of a visitor rather than a co-creator. This remark could equally apply to Stephen, but possibly less so to Madeleine who had been more interactive.

At the end of the ‘happening’, parts of the dismantled installation were given to Stephen, Madeleine and Ezra to keep.

vi) Discussion of the ‘Happenings’

Schieffelin has argued that ‘performance embodies the *expressive dimension of the strategic articulation of practice*’ (1998:199, original emphasis). This leads to a breaking down of the division between ‘performance’ and ‘practice’. Such ‘happenings’ as those described above can be viewed in a similar way, in that they occupy the liminal space between ‘aesthetic performance’ and everyday ‘practice’. This was partly accomplished in some instances through the dispersal (or even elimination) of the audience function, which could be seen most clearly in ‘Untitled’. ‘Coincidences’ had a much more discernable audience/performer divide, which was quite possibly the result of the involvement of a professional choreographer from outside Entelechy, with a more traditional approach focusing on product rather than process. The fact that the ‘Coincidences’ performance was able to incorporate the transition of an ‘audience’ member into a ‘performer’ shows that there was some room for experimentation, although a new aesthetic was not necessarily reached as participants still remained within fairly subscribed roles.

The ‘happening’ which I have described in most detail, Incredible Journeys, can again be seen to drift from an emphasis on ‘process’ to one on ‘product’. As the ethnography shows, the project was highly orchestrated and directed by Entelechy’s facilitators and invited artists. The original intention (on the part of Entelechy) was to create a very self-conscious ‘ritual’, but the small number of young disabled participants, and lack of

their non-disabled peers, caused a change in the direction of the original idea. The aim of fusing everyday, pedestrian actions with aesthetic activity was achieved to an extent, although there was some objection to framing 'performative' moments, where it was unclear whether the participants knew they were performing. Ernst suggested that Madeleine talking into her tape recorder was a 'multi-layered performance', but that it couldn't be reproduced: 'She was relating to it as if it were a person'. He said that the facilitators were viewing the people involved from a performative perspective, and that it was important not to exploit something that was private, and turn it into a 'performance'. During this project certain moments occurred when the people with profound and multiple disabilities were engaged in creative acts where they were clearly communicating 'something': for example, Madeleine's reaction to her own voice recording and the consequent interaction with herself; Stephen making vocal sounds into the microphone in response to Rebecca, Chet and Lucy; and Ezra singing Turkish songs and crying when he remembered people from his past. The work of Entelechy aimed to validate such moments, by framing them as 'performances', thereby seeing them as culturally meaningful, as opposed to random accidental or incidental expressive events. In the Incredible Journeys there was no clear distinction between audience and performer, though some participants were more 'passive' than others. The desired 'drop in' quality of street performance was only achieved to a limited extent with an invited 'audience'. The disabled people were involved in the process of the creation of the installation to an extent, but were heavily guided by the performance artists. They took part in the actual product, the 'installation', in a limited way, interacting with some of the exhibits, but not actually building them, which was left to the non-disabled members of the group (although images and objects which they had created earlier in

the project were incorporated). All the disabled young people involved in the project would be described as 'vulnerable', and to a large extent they were buffered from the outside world by a web of kin and paid carers. The virtual exclusion of the general public by the event organisers was apparently felt necessary in order to protect the disabled people from the unpredictability of an uninvited audience.

Some members of Entelechy's management board were invited to view the installation, in addition to a representative from Lewisham Council, which had funded the project. The Council representative spent some time with both the facilitators and participants, and commented that he was very impressed by the range of 'vocabularies' present at the installation. However, David Slater remarked: 'It was like cooking a meal and nobody came ... But then we didn't really expect guests'. Although this conveyed some disappointment on his part, he did feel that several types of journey had been reflected in the project; the journey of Madeleine from Ghana, the journey Ezra was to make to Turkey to get married, the journey of the three participants into adulthood, and the journey made by everyone connected with the project in getting to know one another.

The Incredible Journeys project was improvisatory and experimental, with its focus changing throughout its different stages. The agency of the participants (specifically those with a disability) was constantly in question. No obvious 'initiation' took place, although this is consistent with the incremental transition to adulthood in British society (see Jenkins 1989). If increased independence and autonomy are taken as markers of adult status in Western society, this cannot be seen to have been achieved, as all three participants continued to need high levels of care and attention. Entelechy, the care

workers, the parents/families and the people with disabilities, all had different reasons for participating in the project and expected differing outcomes. Entelechy's focus was on an aesthetic experience as well as a social one, whereas the other parties involved were more focused towards social activity. The central goal of all of those involved in the project appeared to be an increase in the number of social contacts for these three young people, which could be seen as having been achieved to a limited extent in that they had met each other, the performance artists, a few volunteers, and different carers. Whether or not these newly forged relationships would be continued after their involvement in the project, however, was questionable. The fact that issues concerning transitions to adulthood were raised at all could be seen as a positive outcome of the project, vocalising and focusing on that which is usually left unsaid or unrepresented. It is possible that the idea of journeys or transitions to adulthood was too abstract a theme for the disabled participants. The project came to be more about the immediacy of experience, exploring multi-sensory stimulation, and attempting to open up the aesthetic, re-embodying the perceptual experiences of all those involved. In the example of Incredible Journeys, it seemed to be the case that the displacement of the audience function and the ambiguity of whether the disabled participants were active or passive in the installation, reduced the performance efficacy.

All of these 'happenings' had a common thread of trying to increase the 'relatedness' of various groups of people, transiently forming what Slater (following Turner) referred to as 'communitas'. It was apparent, however, that the desired improvisatory or spontaneous edge often seemed to disappear as the projects progressed. Issues of 'authenticity' in performance were raised by Entelechy and invited artists. Through

eliminating the audience function and attributing all of the participants with agency and intent, ‘competency’ as such was, hopefully, less of an issue. The fragility of this aesthetic space where *communitas* could occur was demonstrated in one of Entelechy’s training workshops where a ‘happening’ was simulated to illustrate Entelechy’s methods to other practitioners (including carers, managers, artists, and therapists), discussed below.

vii) ‘Primal’ art : ‘Rationality’, ‘Choice’ and Sonia’s Dress

Dance work recognises this intelligence of the body and the senses as a legitimate form of communication and artistic expression alongside the verbal and intellectual in society.
(from Entelechy document)

I have a child in me ... I am at liberty to express that. (Rebecca Swift)

Existing concurrently with the metanarrative of ‘tragedy’ in disability performance, is the discourse of ‘authenticity’ and ‘the primal’. Learning disabled people are frequently taken to represent ‘raw emotion’ and are considered to be instinctual and closer to ‘primal’ human nature. This has several consequences when such people are engaged in the arts, particularly performance. They represent a more ‘primal’, ‘authentic’ state of humanity, and are believed to possess an inner consciousness which is revered by some (non-disabled) artists who regard this as desirable in their own performances. At the same time, their art is seen as of ‘the Other’, with critics struggling to incorporate the performance into a known aesthetic. Traditionally, this type of cultural activity is cordoned off from mainstream aesthetics and placed clearly within therapeutic paradigms. Action (or transformation) is seen to take place at the individual rather than societal level, as it is the learning disabled participants who are regarded as ‘in need’ of transformation. Entelechy attempted to reverse this and focus the notion of

‘transformation’ at a societal level, in the tradition of the theatre practitioners Boal and Moreno, discussed below. However, change at an individual level was where this was most noticeable, and the wider effects were frequently questionable.

The major issue which arose in this type of performance appeared to revolve around the notion of ‘intent’. That is, were the performers aware that they were performing, or was the performance ‘framed as’ such by facilitators? The work of the visual artist, de Kooning, who suffered from dementia, raises the issue of the differentiation between the ‘primal self’ and the ‘intentional self’. When the creative process involves a consciousness which has been ‘split up’, either intentionally or due to pathology, what is created may have meaning for the artist, or it may not. What, I suggest, Entelechy were trying to do in much of their work was to tap into what they believed to be the ‘primal’ creative self, and create ‘performances’. These ‘performances’ may or may not have meaning for the disabled subject, or for an audience, but were concrete (though frequently transient) representations, confirming that the subject was alive, creative, and consequently, human. Ignatieff, writing on de Kooning, in 1993, comments that near the end of his life, de Kooning was: ‘unable to recognise anyone or speak, yet he continued to paint. The question was: did these paintings deserve to be called art?’ (Ignatieff 1993:149). De Kooning produced ‘other worldly’ paintings, containing swirls of colour, which divided his critics in their opinion as to whether or not they were ‘art’, and whether or not these were the result of a conscious process. Ignatieff poignantly asks the question whether something can be called ‘art’ only if it is the product of conscious intention, and points out that: ‘The whole direction of twentieth century art has been away from conscious intention towards unleashing the spontaneous, infantile

and subconscious sources of creative energy...' (ibid.). Ignatieff considers that the work of de Kooning 'raises the possibility that art might still exist where there is no artist; that a painting might still be painted where there is no self to do the painting ... de Kooning's brush might no longer be connected to an intentional self, but rather to the deep structures of his own creative inspiration' (ibid.: 149-50). It seems evident that different states of consciousness produce different forms of art. Entelechy would not presume to judge whether or not their performances were 'good art' or 'bad art', simply that they were 'art' and that people with learning disabilities operated along different aesthetic norms.

There is a dilemma, therefore, in viewing such creativity as of 'the Other', and seeing people with learning disabilities as representing a more 'primal' self, an issue discussed in chapter 6 in relation to the film *The Idiots*. If people with learning disabilities are to be proactive and included in creating an expanded aesthetic, they will have to work against suggestions that such activity exists only as either within therapeutic or charitable paradigms, or as a form of voyeurism of 'the Other'.

As shown in Chapter Two, learning disabled people's treatment is inextricably linked with two major discourses, namely 'rationality' and 'development'. Evidently this history influences current social policies in profound ways, particularly that of *normalisation* on which the majority of care for people with learning disabilities is now based. As discussed previously, the core idea is that the 'abnormal' can be assisted to behave in a 'normal' way, and thus become an accepted and valued member of *the community*. Performance art/theatre is an arena in which such 'norms' can be

challenged. This can be seen in the work of Entelechy, who, by providing space for experimentation and moving away from traditional cultural modes of communication allowed roles to be played with.

The tension between normative, therapeutic and aesthetic ways of interacting with people who have profound and multiple learning disabilities can be illustrated through the example of one of Entelechy's training workshops (Between Two Worlds - BTW), which had the aim of disseminating practice at a national level to those involved in statutory and voluntary services. These training workshops often included a performance or 'happening'. In the workshop referred to here, a multi-sensory installation was created by some, but not all, of the facilitators and participants in the hall of the Greenwich Dance Agency. Members of Entelechy used various materials, including saris, scarves, mats, a rope, various percussion instruments, electronic recording devices and textured pictures. One of the key performers who came to dominate the 'happening' was 'Sonia', a middle-aged woman who had Down's Syndrome. Sonia put on a wedding dress, which was part of the installation, and danced and sang with the musicians. The participants (people with learning disabilities who had been invited specifically for the 'happening', and non-disabled people) explored and interacted with the installation for about an hour.

At the end of the 'happening' everyone involved met to discuss the afternoon. During this discussion it became clear that the event had produced strong emotions in many of the non-disabled participants. Three of these people felt so uncomfortable with the

‘happening’ that they sat on the periphery, and did not join in physically. One of these ‘observers’ said:

I couldn’t translate it into the context I work in ... It brought up issues such as ‘age-appropriateness’ ... I’m coming from a Social Role Valorisation⁷⁵ background ... it’s about what we would feel comfortable doing ourselves ... for example, Sonia in that dress ... she didn’t need an accessory to express her talent ... it made me feel that I was watching some spectacle. Sonia has an innate talent ... she doesn’t need all that paraphernalia.

Another ‘observer’ participant commented:

If you’ve got a lot of people looking like Charlies, then its OK ... this lady may have chosen to wear that dress, but what if she had realised the consequences? ... Would she want to look like a sugar plum fairy?

The issue of ‘choice’ when engaging in this type of arts practice with people with learning disabilities is obviously very important. In response to the comments made by the workshop participants, Rebecca stressed that she felt that Sonia should be given the choice of wearing the wedding dress, even if it was interpreted as not ‘age-appropriate’ by some of the audience. Several other participants, including Entelechy facilitators and sessional artists, felt that the ‘happening’ had been staged and was therefore somehow ‘inauthentic’. Entelechy felt that the desired sense of ‘relatedness’ (or *communitas*) had not been achieved because several participants had sat at the edge of the performance space, and that this had worked against the ‘happening’.

viii) Beyond Therapy

Therapy (which implies a prescribed course of treatment of a condition that produces ‘ill health’ with predetermined expected results for a specific diagnosed condition) and the art(s) (which at least in part suggests an exploration, one that usually finds the notion of predetermined expectation an anathema) are strange bedfellows. Happily, more and more people are becoming aware that being involved in creative activity (i.e. the *process* of creating) is every bit as important and in many cases more important than the end product.

B.Warren 1997: 275

⁷⁵ That is, her practice was based on *Normalisation*.

Warren suggests that until very recently in modern industrialized societies, the role of 'the arts' in health has been extremely limited. Over the last three decades, he asserts, people have generally become more aware of their creative potential, with each act of creativity reaffirming the self. Parallel with this, however, is the rise of the need to provide 'justification and tangible proof in almost everything we do. In the arts this has led to the "therapy defence": the need, when questioned, to validate the use of the arts and other creative processes (particularly in professional environments) by describing all creative activity as therapy' (ibid.).

According to Waller 'art therapy' is a diverse collection of practices which are held together by a belief in the 'healing value of image-making'(1991:3). It can be seen to focus on both a practical activity, as well as processes involving the unconscious. There has been historically (since around the 1940s) a split in arts therapy between those practitioners who emphasise 'image-making as therapeutic in itself (Hill *et al.*) and those who saw the art object as both integrative and healing, and also as an aspect of the transference relationship between the therapist and patient (Champernowne *et al.*)' (Waller 1991: 7). Entelechy's work did not subscribe to any psychotherapeutic school of thought, and cannot be seen as 'art therapy'. Aesthetic products (such as paintings) were not interpreted or imbued with specific meanings, seen as representative of some inner conflict, but instead seen purely as acts of communication . However, what it did share with the 'art therapy' described by Waller was an interest in exploring consciousness through aesthetic means, and valuing non-verbal communication in the form of paintings, dance, and movement. Entelechy sometimes expressed the outcomes of their work in what could be interpreted as 'therapeutic' terms, but, like Warren's

suggestion above, they were more interested in an holistic approach to creative activity. It is my contention that although Entelechy's facilitators did not profess to be 'therapists' in the Western psychotherapeutic usage of the term, they did aim to be 'healers', using 'the arts', and specifically 'performance', as a transformative medium to inculcate changes at individual, cultural and societal levels. This has parallels with Taoist healers who create a 'relationship' rather than a 'diagnosis' (see Warren 1997).

When I interviewed Entelechy's arts practitioners about the therapeutic content of their work, the general consensus was that the work they did with learning disabled people was about 'play', as opposed to 'therapy', which was seen as doing something to someone. For example, Rebecca Swift talked about her work with people with profound and multiple disabilities in the dance and movement workshop, Ambient Jam⁷⁶:

When focusing on one person, moving their arms for them in order to get their body straighter, this does move into physiotherapy ... but our work is more art based. Through a movement improvisation with music, members can choose to move their own bodies, in the way they want to express themselves. Bodies can straighten out naturally as a consequence of the focus on play.

David Slater expressed the view that 'the arts' have a kind of 'protocultural' role, suggesting that there can be a difference made to both the individual and the socio-cultural order, moving away from 'therapy':

It's to do with the individual making a mark on or with other people in their society ... and maybe in that process there is therapeutic gain for the individual ... for people with learning disabilities who perhaps don't have particular needs ... I think that [therapy] can serve to disempower and stigmatise, if it is just used as a way of passing time for people that no one else knows what to do with ... I think that in our practice we've always been interested in the relationship between the individual and other people who

⁷⁶ Examined in Chapter 5.

they could engage with outside of themselves ... whether that's in small networks or broader groups ...

David, therefore, saw 'therapy' as a mechanism frequently used in institutions and day centres to contain and control people with learning disabilities, as opposed to a creative cathartic device. However, much of Entelechy's work has a great resemblance to the overtly 'therapeutic' work of the theatre practitioners Boal and Moreno, which could also be seen as 'protocultural'. Boal has explored the links between 'therapy' and 'theatre' and argues that the theatre provides an 'aesthetic space' where self/other relationships can be explored, including the desire for change in the quotidian, the therapeutic effect residing within the dynamic of seeing and being seen: 'Aesthetic space exists whenever there is separation between the space of the actor and that of the spectator, or when there is a dissociation between two times' (Boal 1990:28).

This intermediary 'aesthetic space', Boal argues, is the locus of symbolic realization before being transformed into everyday life. This provides the space for subjective and objective realities to meet in human experience, and for the person concerned to be an active protagonist in their own life. Boal's work cannot be defined strictly as 'therapy', as there is no clear definition of roles, such as therapist and client. Neither is there a clear goal such as relief of the client's symptoms, nor an agreed upon time-span for the treatment. However, it does promote 'healing' in a socio-political sense. Boal asserts that through theatre-therapies, the protagonist can be transformed from a state where he/she is an object of: 'prescribed social and psychological, conscious and unconscious states to becoming the master of these states' (Boal 1990:39).

In Boal's *Theatre of the Oppressed*, the aim is to subvert and transgress oppressive social structures through action. This may be the aim of much of Entelechy's work, but the outcome is difficult to assess, as processes are very subtle. For example, there may be changes in the way in which a care worker views his or her particular client after seeing them involved in a creative event, or a member of the public may feel empowered to attempt to communicate with someone with whom they thought communication was totally impossible, through participation in the creative arts. The aim of Entelechy was for these events at an individual level to feed into and inform practice at a group or even societal level, which would be made possible if enough people were exposed to such 'happenings'.

Entelechy's practice, though not explicitly based on any therapeutic tradition, does, as mentioned earlier, have some comparisons with the work of Moreno (1985), the originator of psychodrama. For Moreno, catharsis can be liberating, invoking a 'therapeutic society'. Reality is first tested in small groups of performers (such as in Entelechy's workshops), later transferring this to everyday experience, and the wider level of *community* and society. There is, therefore, a distinction being made between 'healing' at an individual, pathological level, and 'healing' at a societal level. It is at this juncture that Entelechy appeared to operate.

Like theatre, the process of 'healing' has been compared to ritual, or rites of passage, 'drawing attention to the creative chaos at the rite's centre by means of which an existing psychosocial context is effectively destroyed so that a new and as yet unknown world of personal and social experience may come into being.' (Grainger 1999:131). As

the ‘happenings’ in this chapter, and projects described in later chapters, show, Entelechy created situations of ‘antistructure’ (Turner 1994) where people who deviate from the mainstream of society could interact with professionals and their non-disabled peers, creating new platforms for social engagements which would not normally happen in the course of everyday activities:

In liminality, *communitas* tends to characterize relationships between those jointly undergoing ritual transition. The bonds of *communitas* are anti-structural in the sense that they are undifferentiated, equalitarian, direct, extant, nonrational, existential, I-Thou (in Feuerbach’s and Buber’s sense) relationships ... *Communitas* ... tends to ignore, reverse, cut across, or occur outside of structural relationships.

V.Turner 1994:274

Turner (1969) distinguishes between the ‘liminal’ and ‘liminoid’, with ‘liminal’ activity having the ability to invert but not subvert the established order, whereas ‘liminoid’ situations are more playful, contingent and subversive. These ‘liminoid’ spaces are utilised to experiment with new forms of communication between disabled and non-disabled people, which can then in turn be used to influence interactions and engagements in wider society. The phenomenological space in traditional theatre between the spectator and the performer is renegotiated in much of Entelechy’s work (particularly as illustrated in chapter 5) to bring about a situation where both parties are interchangeable, and in which the categories of disabled bodies and non-disabled bodies can be rearranged or experimented with.

Turner argues that: ‘man (sic) is both a structural and an anti-structural entity, who *grows* through anti-structure and *conserves* through structure’ (Turner 1994:298). How then, would revolutionary performance practitioners such as Boal view this scheme of things, if Turner is saying that there is a system in existence in all societies where the safety valve for social disquiet is antistructure or *communitas*? Are catharsis and

antistructure the same thing? In catharsis, the spectator is purged of pity and fear through identification with the character in the drama. Catharsis is therefore not necessarily revolutionary, as it often works on an individual emotional level. Antistructure and *communitas* have greater potential to be revolutionary as they operate at the societal level, and are more about forging equalitarian bonds than about emotional release:

Ritual and its progeny, the performance arts among them, derive from the subjunctive, liminal, reflexive, exploratory **heart of the social drama, its third, redressive phase**, where the contents of group experiences ... are replicated, dismembered, remembered, refashioned, and mutely or vocally made meaningful ... True theatre "at its height signifies complete interpenetration of self and the world of objects and events." When this happens in a performance, there may be produced in audience and actors alike what d'Aquili and Laughlin (1979:177) call in reference both to ritual and meditation a "brief ecstatic state and sense of union (often lasting only a few seconds) and may often be described as no more than a shiver running down the back at a certain point." **A sense of harmony with the universe is made evident, and the whole planet is felt to be in *communitas*.**

Turner 1990:13 (my emphasis)

Catharsis can be seen as inherent to antistructure rather than analogous to it. Turner asserts that catharsis can occur in *communitas* when there is an exchange of qualities between the physiological pole and the ideological pole of ritual symbols, making: 'desirable what is socially necessary by establishing a right relationship between involuntary sentiments and the requirements of social structure. People are induced to want to do what they must do' (Turner 1994:56). I suggest, therefore, that catharsis and *communitas* or antistructure can be seen to have similar features and are not in themselves revolutionary. It is only by stepping outside of this system of 'redressive action', to a point where spectator and actor are seen to merge, is the revolutionary change which Boal desires likely to occur. In performative moments, such as those occurring in Entelechy's 'happenings', I suggest the participants go some way towards achieving revolutionary transitions by blurring the distinction between audience/performer and disabled/able-bodied. However, the impact of such action is

limited due to the relatively small number of people taking part, and the various social and material obstacles in place. Through Entelechy's training workshops their work was disseminated to a wider audience, and therefore had the potential to impact to a greater extent on the lives of people with learning disabilities across the country, letting antistructure inform structure.

'Therapy', therefore, can be used as a very broad metaphor, which can encompass 'positive' individual and societal change, but can also take on a political dimension. The ability of Entelechy's work to 'transform' individuals with learning disabilities, for example by building confidence, fostering artistic talents, or increasing their participation in the social world around them, was emphasised by Entelechy's practitioners in evaluation meetings and reviews. This theme is further explored in chapter 7.

ix) Emergent realities

The emergence of realities in performance and their movement into the domain of social historical events ... constitutes the movement of ritual or symbolic efficacy into the human world. This is true even when what emerges in a given performance is not necessarily predictable or is even the opposite of the performer's intentions.

Schieffelin 1996:81

Of all the artistic forms, Boal asserts, theatre is the most coercive. It can act, he argues, to eliminate the revolution before it takes place. Boal proposes a new poetics therefore, which can accommodate societal change. He argues that in a society it is the art of the 'dominant class' which is the dominant art, as it possesses the means of dissemination. If 'culture' is taken to mean the symbolic aspects of human society (e.g. rituals, beliefs,

values, leisure activities, and material goods), culture can be seen as a 'signifying system'.

Williams has suggested that culture consists of both 'known meanings and directions', and 'new observations and meanings, which are offered and tested' (Williams, 1989: 4). In this view, therefore, culture is both 'traditional' and 'creative'. What then is the relationship between 'culture' and 'society', and can 'culture' inculcate societal change? From a Marxist perspective, the material base of culture has traditionally been focused upon, whereas other theories have attributed 'culture' with greater autonomy. More recent Marxist accounts of culture, stemming from the 1960s, have developed ideas based around the work of Gramsci, and his notion of 'hegemony' described in his *Prison Notebooks* (1976). Gramsci's 'hegemony' suggests that capitalist domination is achieved through a combination of 'coercion' and 'consent': 'through its direction of the production and consumption of culture' (Barnes et al 1999: 184). Williams' concept of 'cultural materialism' has also been highly influential in analysing the material means of cultural production and cultural forms. Cultural practices, such as the arts and media, are seen by him as not necessarily derived from a separate social order, but instead frequently contribute to its production and confirmation, at the same time as allowing for the creation of new possibilities.

x) Performance Efficacy

The data presented above suggests that the progressive direction for the analysis of disability and performance lies in the complex dialectic between 'audience' and

‘performer’, which was briefly explored in relation to the performing disabled body in Chapter Two. In some respects, Entelechy have sought to disperse or even eliminate the ‘audience function’ in much of their work, and, as will be shown further in the next chapter, claim to bring all participants to a similar cognitive state or ‘communitas’. The aim of this, Entelechy suggested, was to blur the boundaries between care-giver and cared-for, making way for a reappraisal of roles in both performance and everyday life.

The dialectics of audience/performer, and the possibilities for political action and social transformation of the ‘oppressed’, specifically in relation to learning disability, need to be seen within the context of the Western theatre tradition⁷⁷, touched upon earlier. This incorporates both influences on disabled activists and the cultural interventions of ‘enablers’. Schieffelin has written about the framing of reality and illusion in ritual and performance, suggesting that the Western academic view of ‘performance’ holds as fundamental the division between:

(relatively active) performers and (relatively passive, but emotionally responsive) audience. In Euro-American (basically Aristotelian) tradition this divide is also a metaphysical, even ontological, one between a world of spectators which is real and a world conjured up by performers which is not, or more precisely, which has another kind of reality: a virtual or imaginary one.

Schieffelin 1998: 200

Despite being shown to vary both trans-culturally and trans-historically, and being challenged and experimented with by both mainstream and avant-garde theatres, the conventional Western notion of audience and performer persists. This, Schieffelin argues, perpetuates a set of relationships which carry ‘hidden moral and epistemological judgements, when transported into anthropology, that tend to undermine our ethnographic intent (ibid.). This entails Western assumptions of ‘theatre as illusion and

acting as a form of inauthenticity' (ibid.:201). In such theatre, Schieffelin points out, different modes of consciousness between audience and performer are required for the performance to work. This contrasts strongly with the emphasis in Entelechy's practice towards 'authenticity' in both audience and performer, although this was often accomplished through either negating or displacing the audience function in their workshops and 'happenings'. As data in this and the following chapter demonstrates, Entelechy claimed to orient their practice towards shared moments of 'communitas', where roles were relinquished, and their contact improvisation partner's consciousness could be connected with. This could be seen in the 'Untitled' happening, referred to above, whereby Rebecca felt connected to the consciousness of her profoundly disabled dance partner through her pulse.

Partly due to the influence of psychology and psychoanalysis upon Western culture in the twentieth century, academic and public debate has moved away from questioning whether certain groups of people have a 'soul'. There is, instead, a desire to understand the inner 'subjectivity' of others, to connect with their 'consciousness'. When this is very difficult, for example, in the case of people who are deaf-blind from birth, the common reaction by those who can talk and see is to become very frustrated. Pity often overrides attempts at comprehension. According to Varela (1995), Cartesianism, which permeates how minds and bodies are conceptualised in the West, assumes that humans think rationally and linguistically. This suggests that linguistically produced thought controls movement, and that non-linguistic communication is non-rational. If it is non-linguistic, opportunities for producing 'meaning' in any shared cultural sense are, by

⁷⁷ Including the genre of performance art, discussed earlier.

implication, extremely limited. This would suggest, therefore, that there is no meaning in motion. This is evidently not true, as Varela (1995), and others have demonstrated⁷⁸. Rebecca asserted that as trained dancers and theatre practitioners, they (the Entelechy facilitators) were supposedly used to communication: ‘on a “deeper” level within a public context. We are taught, I hope, to relate to and tap into the undercurrents of communication which are emotional, physical and non-verbal, as well as atmospheres and the invisible energies that transfer between audience and performer’ (from Entelechy document). The emphasis in such encounters, for Entelechy, was on physical and emotional ‘intelligence’, an issue that is explored further in Chapter 5

Schieffelin asserts the need to problematize the participant/performer relationship, and that this must be investigated ethnographically rather than assumed analytically:

[F]or anthropology, these relationships need careful investigation – both in formal performances and in everyday life – because it is within these relationships that the fundamental epistemological and ontological relations of any society are likely to be implicated and worked out: because this is the creative edge where reality is socially constructed.

Schieffelin 1998:204

Disability arts, and the work of ‘cultural interventionists’ such as Entelechy, need also to be seen in relation to British alternative and community theatre, which was fuelled by ‘the international counter-culture of the late 1960s and early 1970s’ (Kershaw 1992:36). One of the major offshoots from the alternative theatre tradition was ‘community’ theatre, addressed in the previous chapter, which informs much of Entelechy’s practice. David Slater also drew on the work of Turner, and I observed him reading Turner’s *From Ritual to Theatre* when preparing for the ‘Incredible

⁷⁸ See, for example, the edited volume by J.C. Desmond, ‘Meaning in Motion’ (1997).

Journeys' project. Thus, like other recent arts practitioners such as Schechner, Entelechy was drawing on anthropological theory to influence its theatre practice, and this can be seen as part of a wider post-modernist trend of intercontextuality.

Hastrup argues that: 'In anthropology it has often been stressed that theatre has developed from ritual, and that both are in some sense an answer to people's need for "communitas" and spectacle' (1998:31). In his book *Dramas, Fields and Metaphors*, Turner explained how, in his analysis of the Ndembu, he combined a metaphorical model derived from theatre with van Gennep's process based structure, to form a model of what he has termed 'social dramas', which involve processes of breach, crisis and faction formation, redress, and reintegration. Turner's interests have led him to explore the relationship between life and art, and he suggests that life and art do not mirror each other in a planar way, but in a matrical way:

At each exchange something new is added and something old is lost or discarded ... the interrelation of social drama to stage drama is not an endless, cyclical, repetitive pattern; it is a spiralling one. The spiralling process is responsive to inventions and changes in the mode of production in the given society.

V.Turner 1990:17

Turner suggests that this model is open to 'manifold manipulations', for example, if redressive action fails there may be a return to the original crisis situation. Ritual is seen by Turner as the most common form of redressive action, and it is from this phase of the social drama that his ideas about theatre and performance are drawn. Release from socially prescribed roles is achieved in this liminal phase, leading to the egalitarian and invigorating state of 'communitas'. Spectators are placed in a position where events are both real and not real, and are therefore in a '*ludic*' role (Turner 1982), in which state the spectator can play around with societal norms and regulations. Turner's idea

of 'communitas' has, however, been challenged by Bloch (1974) who asserts that ritual acts in a restrictive way and produces conformity; and also by Sallnow (1981) who argues that 'communitas' contains competing interests and entrenched political differences. This is similar to Boal's criticism of Aristotelian *poetics* in that emotional catharsis is seen as preventing any real structural changes in society. According to Kershaw, however, Turner is arguing that 'the ludic role of spectator turns performance into a kind of ideological experiment in which the outcome has no *necessary* consequence for the audience. Paradoxically, this is the first condition needed for performance efficacy.' (Kershaw 1992: 24). Kershaw asserts that it is the ludic quality of the audience's role, as suggested by Turner, that:

Allows it to engage with ideological difference, that allows rules to be broken (via authenticating conventions) while rules are being kept (via rhetorical conventions). This paradox links theatrical performance to carnival and other forms of public celebration which are designed to produce what Victor Turner has called *communitas*: **Primarily 'a direct, immediate, and total confrontation of human identities'** (Turner 1982:47).

Kershaw 1992:28 (my emphasis)

According to Kershaw, the efficacy of a performance on an audience may be difficult to discern, and he suggests that there may not always be direct consequences of 'possible' worlds impacting on the 'real' world. He asserts that audiences have a 'choice' as to whether a particular performance is efficacious for them, due to their ludic role. However, if a performance resonates with a spectator's ideological beliefs, the impact will be great, and if the whole audience is affected, Kershaw argues, this may impact on whole communities, eventually leading to change at the level of society.

The alternative arts movement, especially the theatre of minority groups, I suggest, may deliberately set out to disrupt conventional models of performance, especially playing with the location of redressive action. For example, if these models are applied to

people with disabilities, are they transformed by the performance, a rite of passage, making them not-disabled? Obviously this is not the case. Alternative theatre, such as feminist performance, black performance, and gay performance all try to communicate the experience of being marginalized. The gaze of society is directed at that which constitutes difference. I suggest that, although it bears many similarities to other non-mainstream performance, disability arts is unique in that the gaze of society is underwritten by the medical model of the disabled as somehow tragically flawed, and in need of healing. Various arts therapies exist which try to 'transform' the disabled, and these take a similar form to a *rite de passage*. Behaviour may be modified, but the 'essential' disability is still there, as bodily stigmata cannot be removed, only 'bravely' overcome. Many disability arts companies overtly critique 'therapy' and the medical model of disability. They are aware that people with disabilities are often perceived as grotesque, and they parody their status as 'freaks' (as Strathcona's *Id* and Fraser's *Sealboy Freak*, described in Chapter Two illustrated), subject to the scrutinising gaze of a paying audience. They challenge the performance aesthetics' ability to transform. It is not the 'viewed' that are in need of transformation, but the 'viewers'. The disabled performers are not displaying themselves in the hope that they will be somehow cured of their affliction, healed in a cathartic exposition. Instead, they are attacking the non-disabled audience's gaze, shaped as it is by both voyeurism and medical objectification. The experimental work of Entelechy, as I have discussed here and in the following chapters, sought to go further in its attempt to change the aesthetic from within. Boundaries between audience and performer were often blurred, setting up provocative dialectics between the perception of 'normality' and 'abnormality' in an 'integrated' arts environment.

In many respects, Entelechy's work could be viewed as a kind of post-modern ritual, involving pastiche and mimesis in an attempt to create a meeting ground for people of greatly differing cognitive and physical abilities. In such work no necessary transformation is incurred, only the showing of possibilities. Postmodernists have challenged the organic models of Turner and Schechner, arguing that cultures are much more fragmented, contested, temporal and emergent. In post-modern performance there is not a clear distinction between where everyday actions end and performance begins.

This could be clearly seen in the work of Entelechy:

Ours is a culture that is so saturated with and fascinated by techniques of representation and reproduction, that it has become difficult for us to be sure where action ends and performance begins. Ours is a world ... of widespread and pervasive simulation, in which the traditional means of separating off instances of performance from instances of the real seem to be compromised, if not wholly superseded.

Connor 1996: 109

xi) Conclusion

As has been shown in the previous chapters, people with learning disabilities in the West are subject to multiple discourses of transformation (i.e. 'differentiation', 'therapy', 'rehabilitation' and 'normalisation'). 'Transformation' as a process, however, needs to be separated out from these medical and social discourses: 'performance', whether or not involving disabled people, is inherently 'transformative', and engagement in such activities can take on a political and radical dimension, as has been recognised by both disabled and non-disabled social and cultural activists. The question needs to be asked, however, as to what effect performance has on the performers, especially if they are a marginalised group, such as the disabled. Disability performance can be seen to act to raise the status of the performers, and to redistribute the balance

of power between audience and performer. Catharsis is not achieved through the evocation of pity and fear among the audience, but instead through an acknowledgement of a shared humanity and a refocusing of the gaze. Disability arts can also be both an assertion of identity and a repudiation of the need to be ‘healed’, where the *rite de passage* of the social drama is turned on its head and it is the spectators who are asked to undertake the transformation from voyeur to sympathetic observer, dismantling the medical gaze towards the disabled body. As the ‘happenings’ above illustrate, as well as the ethnography presented in later chapters, the work of Entelechy often sought to challenge this splitting of agency between audience and performer, particularly in its work with people who have profound and multiple disabilities, illustrated in chapter 5. Their work aimed to create a ‘new aesthetic’, where ‘skill’, as such, was not at issue. Rather, they aimed towards the creation of a ‘liminoid’ space where *communitas* (or ‘relatedness’) could be achieved, and the categories of ‘audience’ and ‘performer’ could be transcended. This was most clearly realised in the creation of ‘the drone’, a trance-like state explored in chapter 5. In chapter 5 Entelechy’s weekly workshops for people with profound and multiple disabilities are examined, in which they sought to expand aesthetics and to disseminate their practice at a wider level through training.

Chapter Five

Movement and Music Work With People Who Have Profound and Multiple Disabilities: Expanding aesthetics/exploring the Sensorium

We experience ourselves, bodily, through the other, as visible to the other and this drives us to stabilize our relationships with them. We can either achieve communicative understanding or try to dominate them. But we must do something because their sheer presence is sufficient to affect us. We cannot help but be involved in mutually affecting relations.

N.Crossley 1997: 27

Emotions ... [*can be viewed as*] ... existentially *embodied* modes of being which involve an *active* engagement with the world and an intimate connection with both culture and self.

Williams & Bendelow 1998:xvi (original emphasis)

i) Introduction

In this chapter I examine Entelechy's work with people who have profound and multiple disabilities, exploring ways of communicating through dance, drama and music. 'Performance', including the issues of 'intent' and 'choice', by and with people with learning disabilities and/or profound and multiple disabilities are further explored. Fieldwork data illustrates attempts to create new aesthetics, and access existing ones. As pointed out in Chapter 1, very little research has been done on the actual lived experience of people with profound and multiple disabilities. This is in part because they are an extremely marginalised group, but also because accessing their point of view, when verbal or written communication is extremely limited or non-existent, is very difficult and time consuming. Re-translating 'non-verbal' communication into the verbal, and then into the written word, for an academic audience is equally challenging.

Anthropologists studying dance and movement in the absence of spoken language also face these problems of finding meaning in motion, as a dancer and anthropologist illustrates:

Writing dance ethnography necessitates abstracting, reducing the multiplicity and chaos of experience to articulate expression, but ethnographic explanations and theories can easily overwhelm the sense of what people do when they dance ... The text of dancing exists in the nonlinear space of memory, and its impressions and structures must be reconstructed by the writer even as they are interpreted ... the meanings and implications of dance, indeed, of all performed art, are embedded in the experiences of the art itself - learning, teaching, creating, performing, watching.

C.J.C. Bull 1997: 270

Entelechy have used the media of dance, movement and music to create communication channels with people who have profound disabilities. As Entelechy's facilitators have pointed out: 'movement - whether for therapeutic or creative purposes - is often one of the strongest forms of communication, as well as a means of contact with other people and the outside world, for people with a sensory impairment' (de Wit & Swift 1995:6). Similarly, Till, a community dance practitioner, asserts that 'everyone, regardless of handicap, is able to communicate and express themselves, at a pre-verbal level, through music and dance' (1994:10). As discussed previously, Entelechy wished to situate such activity beyond the therapeutic paradigms which so often frame this kind of work, especially with people who have profound and multiple disabilities. Entelechy was keen to assert that interactions took place on a creative level as an equal exchange:

Beyond the assumptions of 'difference' which dominate social and artistic policy and actions, there exists the possibility of a new aesthetic language. A creative dialogue can take place between dancers with and without disabilities. Those who are sensory skilled through necessity and those who are sensory skilled as performing artists.

(Extract from Entelechy company document)

It is this 'new aesthetic language' which will now be explored in three fieldwork contexts. Two of these were dance, movement and music groups run by Entelechy on a weekly basis (Ambient Jam and The Diamond Group), which were leisure focused groups aimed at accessing the creative expression of people with profound and multiple disabilities. The third was a training workshop, 'Between Two Worlds' (BTW), held periodically. The aim of this workshop was to disseminate at a national level Entelechy's practice of working artistically with the profoundly disabled, to other artists, care workers and service managers.

A central issue in the lives of many people with profound disabilities, vocalised by some care workers at Entelechy's workshops, was that there was very little time for social interactions in the day to day running of their care homes. This, they believed, reinforced social and cultural incompetence, through lack of stimulation. Many of Entelechy's groups were set up partially with the aim of compensating for this lack of meaningful interaction. Entelechy's rather simple observation, that the more one communicates with someone the better they are at it, has potentially drastic implications if applied throughout care services. Input from voluntary agencies such as Entelechy can be seen to enhance the 'quality of life' of profoundly disabled people, but often causes resentment from carers. This is partly because of the perception that carers carry out the 'hard labour' of caring, whereas the artists, just 'play' with them. Also, as James (1992) has pointed out, care workers distinguish between 'physical labour', and 'emotional labour', with the former being seen as the more legitimate form of paid work.

ii) Emotions in Movement

The idea that art expresses emotions has been current in the West since at least the Romantic Movement, and has been 'given elaborate philosophical defenses in such works as Croce's *Aesthetic* and Collingwood's *The Principles of Art*' (Copeland & Langer 1983:3). A dance critic for the New York Times, John Martin, applied this idea to modern dance in the early 20th century. For Martin, dance 'is the expression and transference through the medium of bodily movement of mental and emotional experiences that the individual cannot express by rational or intellectual means' (Copeland & Langer 1983:3). Modern dance, (stemming from Isadora Duncan), Martin suggests, cuts through 'academic tradition' to the 'source of all dancing'. The modern dance, he asserts, is based on a sympathetic state between audience and performer:

Because of the inherent contagion of bodily movement, which makes the onlooker feel sympathetically in his own musculature the exertions he sees in somebody else's musculature, the dancer is able to convey through movement the most intangible emotional experience. This is the prime purpose of the modern dance; it is not interested in spectacle, but in the communication of emotional experiences - intuitive perceptions, elusive truths - which cannot be communicated in reasoned terms or reduced to mere statement of fact.

J.Martin 1983:22

Martin refers to the phenomenon of shared proprioception as 'metakinesis', to express the idea that:

Movement ... in and of itself is a medium for the transference of an aesthetic and emotional concept from the consciousness of one individual to another ... it is extremely important that we see in the dance the relation that exists between physical movement and mental - or psychical... - intention.

ibid. 23

Such a position has been criticised for assuming that people inherently know the codes for the communication of emotions, and also because much of modern dance is not in fact about the conveyance of emotion. Even when dancers do convey emotion, they do not necessarily invoke this in the spectator. This issue in Entelechy's workshops is returned to later. Entelechy have asserted that many people with profound and multiple

disabilities are experts in this form of communication, and suggest that able-bodied people should become adept at understanding and communicating emotions through this medium of movement and dance.

Since 1989, dance and movement work with people with profound and multiple disabilities formed a central part of the activities undertaken by Entelechy in the London boroughs of Lewisham and Southwark. My involvement with these particular groups covered a period from January 1997 to April 1999. Ambient Jam was held weekly at a local community arts centre on a Friday, and The Diamond Group was held weekly on a Tuesday in a day centre. I attended both groups as a participant observer⁷⁹. Material gathered from interviews with group facilitators and evaluation sessions held after the workshops is also included in this account. The practice developed during these sessions was used to help construct training events such as BTW, and influenced several ‘happenings’ or performance events, including ‘Incredible Journeys’, described previously in chapter 4.

In Ambient Jam and The Diamond Group, professional dancers, volunteers, students on placement, and sometimes care workers, danced alongside people with profound and multiple disabilities. The main genre which was utilised in these two sessions was ‘contact improvisation’, which I describe below. Entelechy’s practice had a phenomenological focus in that it was based on the idea that how a person experiences their body determines how they experience the world. In trying to teach able bodied

⁷⁹ I attended Ambient Jam over a two year period, and it was through this group that I first became acquainted with Entelechy’s work. I attended the Diamond group over a period of 11 months.

participants the basics of contact improvisation in training workshops (such as BTW), emphasis was placed on the awareness of one's body and of those around one, and developing an empathic awareness of how people who have learning disabilities, as well as additional physical and sensory disabilities, experience the world. Sensory and physical disabilities obviously affect their participation in the mainstream aesthetics of performance and the visual arts. As the anthropologist, Howes, has pointed out, 'the contemporary Western aesthetic is almost exclusively visual.' (1991:6). This, he asserts, results in a dissociation of the senses, implying disembodiment, and thus suggests that 'there is nothing healing about most contemporary Western art' (ibid.). Although, as I have already stated, the aims of Entelechy and of my own research, do not intend to present the 'performance' work of people with learning disabilities, particularly people classed as having profound and multiple disabilities, within an overtly therapeutic framework, it needs to be born in mind that the dominant aesthetics within Western culture preclude people with profound and multiple disabilities precisely because of this focus on the visual. If, instead, other sensory experiences are introduced into 'performance', different levels of communication and understanding can be reached, specifically through the medium of touch. To avoid seeing the use of such tactile practices as massage as belonging exclusively to the domain of 'therapy' when used by and with people with profound and multiple disabilities, this needs to be contextualised by the fact that art in many non-Western countries is 'used rather than viewed and the conception of beauty which goes along with this is dynamic rather than static' (Howes and Classen 1991: 265). As in their 'happenings', described previously, Entelechy's workshops attempted, I suggest, to resituate the 'Western spectator-self' (Howes 1991).

People without learning disabilities ‘facilitated’ at all of these workshops (which sometimes became ‘performances’). ‘Jane’, a profoundly disabled woman, who was deaf/blind and had learning disabilities, and had worked with Entelechy for several years, was employed on several occasions to lead the BTW and other training workshops for able-bodied people. It proved very difficult to incorporate her within structured training workshops where a straightforward pedagogical approach was expected, and some participants questioned the degree to which she had consented to join in⁸⁰. However, Paul, Jane’s careworker (who also acted as a trainer in the BTW workshops) qualified her presence by explaining that dance and movement work now formed a large part of her life, and that he felt she was happy doing it. Rebecca added that Jane had been chosen because of her skills as a dancer, rather than the fact that she was disabled, thus again raising the controversial issue of ‘intent’ behind the profoundly disabled participants’ actions.

In order to understand the movement work in these contexts, it is important to explain briefly one of the main techniques used by Entelechy: contact improvisation.

iii) Exploring tactility through contact improvisation

One way in which Entelechy tried to communicate with and access the lived experience of people with profound and multiple disabilities was through the use of a kinaesthetic technique, ‘contact improvisation’. This technique was originally devised by able bodied dancers (its origin is attributed to the performer, Steve Paxton, in the 1970s),

but has also been used by physically disabled dancers. Its use by and with people with profound and multiple disabilities has rarely been documented. Contact improvisation is seen by some participants, audiences and critics as embodying the social ideologies of the late 1960s and 1970s, 'which rejected traditional gender roles and social hierarchies' (Novack 1990:11). The general ideas behind contact improvisation can be explained as:

A form of duet in which the movement is invented by the dancers as they go along, the only rule being that the participants have to keep in close contact with the other's body. Any part of the body can be used to lean against, hang on to or balance on, and the movements can range from rolling over each other, to pushing, pulling, throwing and catching ... it is something in which both trained and untrained dancers can participate.

Mackrell 1992: 145

Contact improvisation differs from other dance forms such as ballet or modern dance in that formal movements are much less prescribed, and it is inherently improvisational.

This dance form can accommodate 'deviant' bodies, due to the fact that :

(it) does not rely on muscular strength, although strength may allow for the execution of certain movements. But because each dancer is supposed to do only what he or she is able, people of radically different sizes and weights can dance quite well together; the key to being a good partner rests on one's movement awareness within the parameters of the form.

Novack 1990:151

This would seem to imply that physically disabled people can 'perform' as well as able-bodied people, if the performers have an awareness of what they can do with their bodies. Touch is a form of communication to which both the profoundly disabled and able bodied dancers have access, and, as Montagu has pointed out, 'Awareness of self is largely a matter of tactile experience' (1986: 390). Much of the daily tactile experiences of this group of people revolve around exchanges concerning care and control. Physical intimacy with another person, except during moments of bodily care,

⁸⁰ Jane was paid a wage by Entelechy when she took the role of a trainer in the BTW training workshops.

may also rarely feature in their lives. Contact improvisation, however, is, in theory, about tactile exchanges on an equal level of mutual exchange, and when this was performed in the workshops with care workers dancing with their 'clients', new dynamics of roles and relationships were explored.

Bull asserts that the genre of contact improvisation shifts away from a focus on the visual, experienced in other dance forms such as ballet by both audience and performer. Instead, 'the movement structure of contact improvisation stimulates the dancer to sense herself in mutual motion with a partner, and the spectator to identify with the sensual, proprioceptive experiences of the dancers' (1997:277). Furthermore, Bull suggests that contact improvisation, irrespective of whether the participants are able or disabled, can produce a sense of what can be understood as 'intercorporeality' among those taking part: 'For the dancer, the body's edges seem to change and to meld with one's partner; likewise, the sense of weight shifts in response to the partner's movement and the movement itself seems generated by and through the points of contact' (ibid.). This, however, is from the perspective of people who can put the experience into words. It is very difficult to know how non-verbal people experience such encounters. Within the workshops such encounters were usually 'framed as' performance by Entelechy, with intent (not uncontroversially) being attributed to their actions, in the same way as it was to the able bodied artists. A consensus rarely existed as to what was actually being communicated, although the expression of emotions such as pain, anger, and pleasure by people with profound and multiple disabilities were generally felt to be correctly interpreted by their able-bodied contact improvisation partners in Entelechy's workshops, based on a shared humanity. As Crossley (1995) has pointed out in a

review of the work of the philosopher, Merleau-Ponty, emotions such as anger are not situated in an inner mental (emotional) realm, but in embodied behaviour. Through dance, movement, and music, Entelechy hoped, contexts could be created where identities could be enhanced and affirmed, and where the lived experience of a profoundly disabled person could be communicated to others through embodied action.

iv) The Ambient Jam Workshops

Approximately eight people with profound and multiple disabilities attended the workshop each week, often accompanied by their care workers. In addition, between two and four people with 'mild to moderate' learning disabilities attended the group in the role of musicians, working alongside the sessional musician, Charles Hayward, as part of his 'Extraordinary Orchestra'. This 'Extraordinary Orchestra' accompanied the dancers, playing on drums and keyboards, as well as singing. The session was very much along the lines of 'free jazz', with contact improvisations sparking off improvisations by the musicians. Ambient Jam was organised by Rebecca, and the movement work was led by sessional dancers employed by Entelechy, in addition to Peter, Entelechy's apprentice, and volunteers or students on placement.

The Ambient Jam group was held in a fairly simple environment with mats and cushions laid out on a bare wooden floor. Materials were sometimes brought in, such as parachutes and rope, and later in the year a projector was used, but generally the room was fairly empty. As Ambient Jam was based in an arts centre, away from The Diamond day centre, Entelechy had a fairly high degree of control over the group and the

comings and goings of its members. Tensions sometimes arose between Entelechy and care staff accompanying the disabled people over issues such as respecting the integrity of the workshop by not talking⁸¹, lifting, health and safety issues, and how best to deal with 'challenging behaviour'.

The paid dancers and volunteers arrived for the session about half an hour before the people with profound and multiple disabilities (referred to as 'members' or 'clients'⁸²). They set up the room, varying the layout from week to week. Nearer the end of my fieldwork, a horseshoe shape was frequently used, rather than a filled in square, so that people in wheelchairs felt more centrally incorporated into the group. This represented a slight shift in the initial bodily positioning of the disabled dancers, as previously everyone was removed from their wheelchairs and placed on the mats, unless this would cause obvious pain. A mechanical hoist was assembled, in readiness to lower people from their wheelchairs on to the mats. Charles arrived before the session began, with his instruments, and set up drums and keyboards in a corner of the room.

Gradually, people would arrive with their support workers, and were lowered on to the mats, using the hoist if necessary, or alternatively support workers and members of Entelechy would help them to take off their shoes and/or splints and assist them onto the mats. The dancers usually worked with one person initially, although sometimes

⁸¹ Care staff were asked not to talk to each other in the sessions by the facilitators. This was more of an issue during the first year of my research in Ambient Jam, as there was more tension between these two groups. Later in my fieldwork, care staff were asked to leave the room if they did not want to join in the session.

⁸² Entelechy referred to the learning disabled people with whom they worked creatively as 'members', whereas social services/care workers tended to call them 'clients', reflecting differing ideologies.

more at the same time, introducing themselves tactilely to the disabled people. They began with gentle physical warm-ups reminiscent of physiotherapy, manipulating the disabled person's legs and arms to 'warm-up' their muscles. Interactions and encounters then took place between the people with disabilities and the non-disabled dancers, leading up to a contact improvisation jam. This included a variety of tactile exchanges, such as weight bearing, balancing, leaning, pushing, massage, mirroring movements, or just lying next to each other, 'tuning in' to each other's bodies. There was very little spoken language apart from accidental and incidental words and phrases, such as when using the hoist, greeting someone or gently talking to someone asking them to calm down. Charles played music which was a collage of sounds. Two or three people with learning disabilities played on the drums and keyboards, and electronic samplers were often placed under people lying on the mats, which would record sounds and repeat them. The room would be filled with fragmented noises and drumming. Christine, one of the learning disabled musicians, would often 'sing' mumbled phrases and disjointed words into a microphone. Sounds were echoed back and forth between the disabled people lying on the mats and the musicians, which included incidental groans and screams.

'Groupwork' movement was attempted in the second half of the sessions, which were more formally structured during the first year of my fieldwork. With the arrival of new sessional dancers in the Autumn of 1997, a looser structure was created, with paired encounters drifting into group experiences in a much more random way. This was considered by Rebecca to be a better format, as it was more about 'performance', and less about 'therapy'. For example, weight bearing contact improvisations were

frequently tried, almost always with the non-disabled dancers doing the weight bearing. Sometimes they balanced the disabled dancer by placing their legs on that person's stomach, suspending him/her in mid-air.

Charles wanted the dancers to respond to the music via movement, but the dancers (both able bodied and disabled) were not always receptive to the music, and responded to different stimuli such as touch, light or smell. During an interview, Charles tried to explain how he felt the music worked with the movement in Ambient Jam. He said that: 'I play to the room ... the music includes movement, sounds outside, light ... intentions. I'm receiving as well as transmitting ... When I work at Ambient Jam its a bit like a composition, but different each time ... the sequence is different, there are new people'. One form which communication took, in both the music and movement in Ambient Jam, was for the non-disabled dancers/musicians to mirror the disabled person/people. The dancers struck up non-verbal dialogue through copying what the other person was communicating, with perhaps a variation on it, until they built up non-verbal 'conversations' through small, often barely perceptible movements, such as the rolling of the eyes or the flicking of hands. About half way through my fieldwork, video cameras and monitors were introduced into the group, so that the disabled people could see themselves moving. In many cases, they interacted with their own video image, 'performing' to themselves in a seemingly self-reflexive way:

I think the video is interesting in that it picks up tiny movements ... Tony and Edward stared right into the video camera for ages. With Tony there were all sorts of things going on in his eyes, they were changing, as if he was almost playing with his image ... I think what would be wonderful is to have the equipment adapted one day so that people like Natasha or Tony could look through it themselves and have a sense of owning the camera

Rebecca Swift

About a third of the way through my fieldwork, the emphasis of the sessions changed slightly towards more play-like activities and incidents that could be ‘framed as’ performance by Entelechy’s facilitators. Siobhan, a sessional dancer, affirmed this. She said that what had worked with some of the people who weren’t as mobile as others, was reacting and inter-reacting with their tiny movements, to make them have a ‘performance’ quality. Rebecca described her experience of this process when working with Natasha, a woman who had cerebral palsy and autism:

It really feels like there is a performance there now ... taking people’s movements as a stimulus ... Natasha is choosing to play ... it’s not about doing something to someone ... it’s about allowing a space where you can feel your own feelings and move with them.

Like the ‘happenings’ described in Chapter Four, the distinction between audience and performer was not clear cut in these workshops. When there was an audience, it was largely a ‘safe’ one, in that it was composed of support workers and/or arts practitioners who were already attuned to the needs of people with learning disabilities. The room where the workshop took place was overlooked on one side by a window, where passers by could see in, and on another side of the room was a nursery school garden, so the performance space was framed by two unusual ‘audiences’, both transitory. Support staff who stayed in the room were usually asked to join in the session, as there was a feeling of unease among Entelechy practitioners if they just watched, although this frequently happened. The ‘audience’ and ‘performers’ were therefore interchangeable, on some occasions at least. Sometimes people with learning disabilities chose to sit out at the side and watch. If support staff stayed in the room, they were requested to sit on the floor and be at the same level as the people on the

mats, thus further blurring the distinction between 'audience' and 'performer'. As argued earlier, the constriction or even elimination of the audience function served, I suggest, to refocus mainstream aesthetic views, particularly around the issue of 'competency' in performance. What seemed to be happening was that the audience/performer divide was displaced physically onto the actual performance area (the mats), making the relationship between participants less prescribed, and allowing for a much greater flexibility of roles.

Charles and Rebecca tried to explain how their workshops were on the edges of 'performance', but sometimes crossed over this boundary and actually became performances:

Charles: I feel that all the time we are doing that workshop thing ... it's not like a teaching gig, "you hold the drumstick like this"... We're there, we're off ... no rehearsal ... it isn't a rehearsal, it's a performance, that's not quite finalised yet ... that's the way I feel about it ...

Rebecca: Charles has just captured the essence of what we are doing in Ambient Jam. It is a performance that's not quite finalised yet.

Charles: For me it is a performance ... it's not really rehearsing it.

Rebecca: Rehearsals ... don't have that heightened feeling of being in the moment and of working very close to survival instincts ... Ambient Jam does, when it works well....

I often entered into contact improvisations, one of which I describe here. It involved myself and 'Michelle', a 40 year old woman who was blind and had profound learning disabilities. She did not talk, but was able to hear, and sometimes hummed in a rhythmical way. She was very vocal, however, and made a variety of noises according to her mood, ranging from high pitched whoops of joy to hollering sounds when she appeared to be distressed. Michelle was described by her carers as having 'challenging behaviour', in that she sometimes hit out at those around her, and harmed herself by

hitting herself on her head or biting herself (she had had all her teeth removed at some point in her life). Here I describe one particular interaction with her:

She thrust her feet towards me, and placed my hands on them. For a while she lay against me, resting her back on my stomach, while she had her feet in the air, legs folded up against her body, wanting me to massage her feet. She then span around and thrust her feet towards me. She did this several times.

The incidence of self-harm and violent outbursts by this woman decreased significantly during the period of my fieldwork⁸³. Entelechy would argue that this was because her involvement in the group had given her a creative outlet through which to express herself, and also provided a space where behavioural boundaries were more flexible than in other areas of her life. This utilisation of aesthetics to express 'emotion' outside therapeutic paradigms could be interpreted as one of Entelechy's major agendas in their work with the profoundly disabled. Additionally, it seemed to be the case that Michelle responded in a positive way towards tactile and aural stimulation provided by the group, through contact improvisation and a form of music which was able to incorporate and reflect her own vocalisations.

⁸³ The start of Michelle's involvement in the group coincided with the time I started my fieldwork. After periods of absence from the group, her behaviour deteriorated, thus reinforcing the claim that involvement in Ambient Jam had a positive effect on her. The frequent changes in her care staff also had an adverse effect on her behaviour.

'Edward', a 36 year old man who had cerebral palsy and was described by his carers as an 'elective mute' (i.e. he chose not to speak), also appeared to enjoy the groups. He was described by his carers as 'tactile defensive'⁸⁴, and initially, Edward was very much a loner. Although he did not like to be touched, he was very aware of other people in the room and reacted to what they did from a distance. When he was very relaxed he sometimes sat himself up, and clapped his hands in time to the music. If the musicians noticed that he was joining in with him, they tried to pick up his rhythms and shape the sounds around him. When he was distressed, he banged his fists against his head. The facilitators tried to bring him back into a calmer mood when he did this, using both music and touch, if he would allow them to do so. During the period in which I observed the sessions, Edward's behaviour in the group changed, and this was noticed by the group's facilitators. One of the facilitators said that she thought that he had become:

Much more present than I've ever seen him ... He sat next to the musicians last week ... which I don't think I've ever seen him do ... and he was clapping ... his support worker was watching him. He was clapping on the beat and he was trying to do it without anybody noticing, and sometimes he was missing a beat because he has bad co-ordination. He was really tuning into the music and I noticed he was very happy to be seen to be sitting there in that role with the musicians.

Indeed, Edward had, during the course of my fieldwork, observably changed from not wanting anyone to touch him, and sitting on the edge of the mats away from other people, to being in the centre of the room, allowing limited communication through touch.

⁸⁴ Such jargon has crept into social services/health discourse over the last ten years or so in an attempt, perhaps, to be less objectifying of the person being described, but often seems to do the reverse.

The facilitators in the workshops were again eager to point out that what was happening was ‘art’ not ‘therapy’, although they acknowledged that the sessions did have a therapeutic effect. For example, it was said on numerous occasions that, through attending the sessions, certain disabled people were moving in ways which would have taken months or years to achieve in physiotherapy (as verified by visiting physiotherapists), whereas the same effect was being achieved in a number of weeks in the workshops. This was explained by the facilitators as being the result of these people ‘choosing’ to move, rather than being coerced. Beneficial effects of attending the sessions were measured in a very loose and generalised way; for example, laughter, smiles, and alertness were taken as signs that a person was relaxing and enjoying the session. Other indicators were taken to be a straightening of the body, through ‘opening out’, during the session as the participant became more relaxed and receptive to what was going on around them; and a reduction in ‘challenging behaviour’ such as self harm. Screams and anarchic behaviour, which are normally read by care workers as signs of distress or something to be controlled, were not necessarily viewed by Entelechy as a ‘bad thing’ to happen in the sessions, as raw emotion was seen as a creative energy and an act of communication. This seemed to concur with Entelechy’s implied idea that such people are more ‘authentic’, linked to primal emotions which artists have the skills to tune into. However, Charles, the facilitating musician, felt that most carers and some artists conventionally think that when working with profoundly disabled people in an artistic way:

... that it’s got to be happy ... They [*the people with disabilities*] would rather get down to some serious stuff than just have a good time and clapping ... they should let the stress through. It’s like allowing people to be the totality of themselves.

Much of Entelechy's work involved attempting to contrive a meeting ground between verbal and non-verbal worlds. One way in which some members of Entelechy described how such a meeting place could be created, was framed in terms of a state which they termed 'the drone'. Charles described the drone as a kind of trance, where thought patterns were released, and a sort of meditative state was entered into. 'The drone' state was reached when the facilitators and musicians had been working with the participants in a workshop for some time. The dancers improvised movements and musicians vocalised sounds which seemed appropriate for that particular time. The people with learning disabilities echoed back these sounds, with obvious variations, which in turn were taken up by the facilitators. Eventually a continuous, uninterrupted drone was produced and held on to by everyone present, including those with profound and multiple disabilities, until this almost trance-like state was arrived at, in which all those present felt at one. This drone state could not be produced at will but was the spontaneous or random result of a successful workshop. Achieving 'a drone' was considered highly desirable and something of a triumph by both the musicians and the facilitators.

Charles felt that when 'the drone' was genuinely achieved by everyone in the room:

... it's a great leveller ... everyone is on the same footing ... instead of working with 'the disabled' we're a mixed ability group. Sounds such as dijereedoo or a drum free people right up ... like finding a home, a bedrock, or a womb, they feel carried and held by that drone note. Everything is in relation to that drone note.

Charles Hayward

A dance facilitator added that the 'drone' could equally be applied to the movement work, 'it's that thing of learning ... structuring, choreographing, improvising, and all of a sudden you let go but the knowledge is inside you and you just bring it out'. The hidden 'skill' of performance is to make actions 'unconsciously', without thinking, as Stewart explains in relation to dance: 'If I instruct my arm to rise my arm is *not* dancing. It is only when I feel the practised neuromuscular pathway through which my arm is already rising that I have a dancing arm' (Stewart 1998:43). For someone with severe physical and learning disabilities this 'skill' may be difficult, if not impossible to master. What, I suggest, was trying to be accomplished in these workshops/performances, was to reach a state where 'skill' as such, was no longer an issue.

v) The Diamond Group

The Diamond group was Entelechy's other workshop for people with profound and multiple disabilities. This workshop catered for a similar client group to Ambient Jam, and also utilised contact improvisation and improvised music. One of the main differences was that it was held in the day centre where Entelechy's offices were based during the first year of my fieldwork. This meant that the day centre had some influence over the composition of the group, and provided some of the funding. It was run by Entelechy as a two-hour session, once a week, on a termly basis. Approximately eight people with profound and multiple disabilities came to the group, most of whom attended The Diamond Centre on a daily basis, although one or two 'members' were brought in from elsewhere. The group was facilitated by Entelechy, and was usually also attended by several care workers.

Rebecca Swift oversaw the running of the Diamond group. Laura, a dancer, teacher and choreographer, was employed to lead the group, she brought along her dance students to some of the sessions. Additionally, Hazel, a local volunteer, occasionally attended, as well as Peter, the company 'apprentice'. Rebecca took part in some of the initial sessions in order to give Laura guidance as to the structure of the group. As the year progressed, Rebecca gradually withdrew from the sessions, although she usually set up the room, leaving Laura, Peter and Hazel to run things. The group was supposed to be attended by a member of the care staff from The Diamond Centre, although this did not happen on a regular basis. Several of the most profoundly disabled people were accompanied by their own individual care workers during the session. For example, Kim had cerebral palsy and was unable to talk or control her limbs, and was also partially sighted.

The group followed a similar format each week. Rebecca would set up the room, a large empty space between Entelechy's office and the rest of the day centre, which was normally used for various purposes such as pottery making and storage. She arranged the room as an 'installation' each week, covering the floor with mats and cushions, and hanging ropes and material such as saris and parachutes from the beams in the ceiling. The structure of the installation was intended to create different performance areas. Peter, however, was opposed to some of Rebecca's elaborate creations, saying that the floor space was the most important thing:

We mustn't get into the trap of 'corridors' where we can't move. It's best if the floor is not littered with fabric and instruments ... I'm looking for a gadget so that sound can

travel across the room like a ball ... we could position the fader over Kim, so that she can feel the music.

Thus, gradually, over the year, the group decided to use less materials and objects in the installation, as they felt the space was becoming too cluttered. It was also noted that the amount of space available to them had shrunk over time, as The Diamond Centre staff were using the area to store bikes and old equipment. The negotiation of the use of the space was a contentious issue, and reflected tensions between the day centre and Entelechy.

None of the disabled members of The Diamond group were proficient at using spoken language, although some made vocal sounds, and one person uttered the occasional word in English or Somalian. The group appeared to have been selected on the basis of their limited communication skills, which led to them being generally ignored in day centre life. Entelechy aimed to give its disabled members individual attention, stimulating them into interactions with other people. A lot of intimate communication took place in the group during some sessions, in the form of touch and massage. Interactions between disabled participants were encouraged, although there was some ambiguity around 'intimate' relationships developing.

Before my fieldwork started, the group had also employed a musician, who had played the piano, but the funding for him was no longer available by autumn 1997. A few musical instruments were strewn about during the sessions as part of the installation which the participants sometimes picked up and played, and occasionally, Ben, one of the disabled participants, brought along his mouth organ. Consequently, there was

music in the group, but of a much more improvisatory and interactive kind than previously. Peter created what he termed a 'soundscape', which entailed trying to make a physical environment which would produce sounds when touched by people with the minimum of physical effort. He used microphones and Astroturf, linking them up to speakers, and also tried to adapt old instruments for use in the group. For example, he covered an old electronic keyboard in material, so that notes could be played by pulling on tassels. He also brought along his guitar, attached microphones to it, and amplified the sound. He tried to encourage members of the group to interact with the microphones, placing them on the disabled people's bodies or near their faces. He received quite a good response from some of them who could recognise the sound of their own voice, and they echoed it back into the microphone.

Once the room had been set up, Hazel and Laura improvised movements in the space, warming up for the session. Peter experimented with his soundscape. In planning meetings it had been agreed that the disabled group members would be brought in at intervals from the adjoining day centre room, by the member of the Diamond staff allotted to the group, so that each person could be introduced individually to the environment. However, this controlled 'introduction' did not usually happen. People coming from outside The Diamond Centre often arrived early with their care workers and came into the room. The member of Diamond staff did not always turn up, and so people were left waiting outside the space. Eventually, Laura or Hazel would go into the adjoining room and bring people into the workshop. Arrivals were introduced to the other participants and people would be slowly helped onto the mats.

Once everyone had arrived in the room, the group facilitators would initiate dance and movement improvisations with the disabled people, utilising items from the installation such as musical instruments and various materials. When I asked Rebecca about the aims of the group, she said:

The Diamond group is about shifting landscapes ... the pulse of the afternoon is about how it shifts ... it becomes a theatre piece ... it has a raw street energy, and this rawness and matter-of-factness needs to be engaged with. Like in Ambient Jam, who are the audience and who are the performers constantly shifts ... It is important to have the space to feel uncomfortable and to experiment ... there are moments of comedy and theatrical improvisation ...

The ambience of The Diamond Group was at a disadvantage when compared to that of Ambient Jam. This was mainly because it took place in a day centre instead of a community arts centre, and the group's space was less defined and was encroached upon by the day centre. It was unfortunate that the group lacked a professional musician, although every effort was made by Peter and others to provide music. The group was discontinued in the autumn of 1998, due to the withdrawal of funding⁸⁵, but I believe Ambient Jam is still in existence today.

vi) Discussion and analysis of the workshops

Novack, a dance theorist, asserts that contact improvisation is appropriate in the context of negotiating identities, and suggests that it has 'constituted a social experiment, an attempt to place dance in a liminal social context which fitted neither the category of theater dance nor the category of social dance.' (Novack 1990:16). What Entelechy was attempting to do can be likened to a social experiment, using a 'liminal' dance form to try to connect 'liminal', marginalised people to the 'cultural life' of their

⁸⁵ The result of cutbacks across statutory services funding.

community. This was partly achieved through the restructuring of traditional modes of workshops and performance, so that there was no clear divide between audience and performers, and the intent was that no one person would direct the action. However, when the workshops appeared to be becoming too chaotic and spontaneous, facilitators often tried to steer the action back to a more manageable aesthetic. Rebecca explained to me that she felt that it was important to create spaces for ‘performance’ between two people, which the rest of the group could watch and observe, while participating in the group at the same time. In some of their workshops the space was structured so as to create different ‘performance’ areas; for example, the different heights of the piano and chairs marked out moveable divisions in the room.

Through reorienting the senses away from the dominant visual mode of Western art, as is the case in the above workshops, Entelechy had sought to shift ‘performance’ from being viewed to being used. Because of the dominance of the distance senses in Western art, when proximity senses are involved there is often a tendency to frame the experience as ‘therapy’, perhaps because it attempts to tangibly ‘do’ something to those involved. ‘Therapy’ was not seen by Entelechy as an intrinsically bad thing, but to frame the experiences I have described as such overrides the very conscious intention (on the part of Entelechy’s facilitators) to move away from a situation where any one person controlled the action; and where ‘healing’ was seen instead as a by-product of creative expression, rather than the focus of the activity. The potential of performance for ‘transformation’ needs, therefore, to be understood through re-embedding the aesthetic within a multi-sensory approach, moving away from straightforward visual paradigms.

Entelechy, I suggest, has sought to re-embody the perceptual experience of all those involved in the workshops/performances. The profoundly disabled person's embodied consciousness was, through touch, accessed by the able-bodied facilitator (but still in an embodied and non-linguistic state). Meaning (whether imagined or experienced as 'real') was then attributed to the profoundly disabled person's actions by their partner, and sometimes by an empathetic audience. The feeling of intercorporeality may, however, only exist as an object of intention in the consciousness of the able bodied. Through being their cultural arbiters, Entelechy attempted to prevent such people from dying a social death. Greater emphasis was placed on all people existing in person-to-person relationships, rather than on mind-to-self relationships. This was partly because of the qualities inherent in contact improvisation, but was also due to the ambiguity of who was performing and who was the audience, leading to a questioning of all roles, such as 'carer' and 'cared for'. This became especially apparent when care workers joined in the 'jam', many of whom were initially uncomfortable at being in a physically intimate situation with another person outside the carer/client relationship. Whether this approach positively incorporated the profoundly disabled within a 'new' performance aesthetic was difficult to say. However, if an ideal state of 'the drone' was entered into, then, in theory, this intercorporeal/intersubjective state was reached by all participants, both able and disabled, and potentially led to a recognition of everyone's dependency on others for their own recognition of self.

Moving away from traditional cultural modes of communication, and attempting to let go of roles, challenges the medical and social services way of treating people with profound and multiple disabilities, and also can be interpreted as in contravention of the

ideology of *normalisation*, as the aesthetic created is not ‘culturally normative’. What then, are the consequences of such activity? Entelechy aimed to challenge the boundary between performance and everyday life, and this was partly achieved by creating liminoid spaces for experimentation. The extent to which people with profound disabilities were ‘integrated’ in the local community through participation in such groups is highly debatable. Small subtle changes can take place in the behaviour of the profoundly disabled, which, to the casual observer, may appear inconsequential. No great athletic dance event took place, but instead, small-scale encounters between people with very limited communication and able bodied dancers occurred. However, care workers have attested that through involvement in dance and movement workshops with Entelechy, small but significant steps were made by the profoundly disabled participants towards increasing their social experience and opportunities for communication. Involvement in the group for people with profound disabilities had also had the effect of enhancing their status in the eyes of their care workers, through noticing abilities which were hitherto unknown. Increased respect from care workers can lead to changes in ‘quality of life’ for their ‘clients’, often in direct response to choices and preferences indicated through the projects by the profoundly disabled person.

vii) Between Two Worlds

These training workshops aimed to provide both an insight into how Entelechy had devised ways of working with people who had profound and multiple disabilities ‘creatively’, and also to give some idea of what it is like to experience such practices as a disabled person. The participants came from various regions of Britain, and included a

mixture of artists, therapists, care workers and service managers⁸⁶, none of whom had (noticeable) disabilities. The first ever 'Between Two Worlds' (BTW) was held in November 1997 at The Greenwich Dance Agency, and was experimental in nature. From this initial experience, further training workshops were developed, and were held in November 1998 and March 1999. (I attended all three training workshops as a participant observer.) I was asked by Entelechy to record what occurred during the workshops and the experiences of participants, so that they could build on this to improve future training.

During the BTW workshops, attempts were made to stimulate all the senses, and to place less emphasis on visual perception. This was done to try to simulate what it is like to have fewer than five senses, and how to relate through the senses on a non-verbal level. The main medium through which the sensorium was explored was 'contact improvisation'. Many insights gained from regular workshops such as Ambient Jam and The Diamond group were utilised in the BTW workshops. Below I describe several key themes which arose in these workshops, which can be used to illustrate core issues surrounding the interactions between the able-bodied and people with profound and multiple disabilities.

viii) Exploring the sensorium

In the BTW workshops, senses other than the visual were explored in various sessions, and other senses were shut off through the use of blindfolds and ear plugs. The participants were encouraged through diverse exercises, mainly based on contact

⁸⁶ See Appendix IX for a breakdown of workshop participants.

improvisation, to 'think' with different parts of their bodies, in the same way that Entelechy imagined a sensorially impaired person would experience the world. For example, the participants were made aware of sound, smell and touch as they explored the workshop space. One exercise which was repeated in all the workshops was where a sensory 'garden' was created in the room. In this exercise the group was divided into two, with one group 'protecting', and the other exploring the space for twenty minutes with their eyes covered. They, therefore, had to use the senses of touch, smell and hearing as their primary means of orientation. Herbs and other smells such as vanilla essence were placed around the room. The 'protectors' played percussion instruments in order to give some spatio-temporal awareness to the people who had their eyes covered, and thus prevent them from straying outside of the closed circle and harming themselves. The groups changed over and repeated the exercise, without immediate feedback. What Entelechy appeared to be doing was rather more than simulation, in that they were trying to awaken all the senses in the participants, opening them up to alternative modes of experiencing the world, rather than solely through dominant visual paradigms. However, such 'simulation' exercises have been criticised by some disabled activists, as Kupperts points out: 'These activists point to the fact that disability means much more than impairment, and that simulation does not take into account disabled people's training and habit with their own specific bodies' (Kupperts 2000: 127). Returning to earlier discussions about the difference between the quotidian and aesthetic in performance, what Entelechy could perhaps be interpreted as doing was trying to re-structure the participants' aesthetic paradigms, focusing on the 'habitus' (Bourdieu 1977) of the human body. The merging of 'practice' with 'performance' is a fertile ground on which to try out new social and cultural relationships, particularly in

respect of people with disabilities, whose ‘habitus’ may not centre around the ability to walk upright or to speak:

Practices have an internal ‘logic’ of their own, which provides the strategic rationality or purposive orderliness of ‘the way things are done’ in most ordinary cultural activity. Collectively, practices form the shape of the unthought behavioural regularities of a cultural world ... Practices can be said to emerge from this ground of habitude in the form of structured or ‘regulated’ improvisations when people deal with the situations in which they are involved in customary practical ways.

Schieffelin 1998:199

Such practices are inherently improvisational, due to situations only ever being analogous and not exactly the same. This moment of improvisation is where ‘practice’ and ‘performance’ merge: ‘Thus performativity is located at the creative, *improvisatory* edge of practice in the moment it is carried out – though everything that comes across is not necessarily consciously intended’ (Schieffelin 1998: 199).

In all three workshops, Jane, who was deaf and blind, was employed as a trainer, as mentioned earlier. She was present during this exercise, exploring the space at the same time as the other participants. The presence of Jane had a noticeable effect on the rest of the participants. Those people who came into contact with Jane attributed to her an almost supernatural tactility, for example, one woman commented, ‘I felt that Jane’s fingertips generated something, almost as if you could feel her sight.’ Her support worker had once said that ‘Jane reads the world through her feet.’ Rebecca added that for Jane, ‘touch is her first language. She is very at ease.’ Another workshop participant asserted that Jane was not just touching and exploring, but was trying to ‘say’ something, but it was open to interpretation as to what that was.

After the exercise the group met to discuss their experiences. Much of the discussion, quite naturally, focused around not being able to see, as illustrated by the comments of some of the participants:

‘It was nice doing something for me, instead of for other people ... I’m usually the one with my eyes open. I became relaxed as the morning went on, when I realised that I wasn’t responsible for others’.

‘I liked the herbs ... the smell made me feel safe ... The mint made me think of my mum’s garden, which was really nice. The contact was nice ... nice spaces, not frightening. When we ‘impacted’ it was painful. I stood still for a while ... I felt like everyone was absorbing the pain off me ... they patted me on my back and rubbed me’.

‘I felt two different things: when I was walking on my own with my eyes covered, this felt scary, but at the same time touching was difficult too, which led to a conflict inside myself ... “I don’t want to be on my own, but I don’t want to be touched” ... I also felt giddy when I was being pulled around ... it was disorientating ... I sought out people who were less dominant with their touch.’

Others who had come into contact with Jane, and had recognised her through touch, commented on her proficiency at moving around. Rebecca said: ‘There is a matter-of-factness about Jane’s touch, which makes me feel at ease’. Several people felt ‘out of control’ when experiencing the world in a non-visual way. In all the workshops, the presence of Jane was noted by the participants, most people experiencing her in a tactile way, which they found comforting. This was probably because she was seen as an expert in this form of communication, and therefore, people felt somewhat guided by her, but, paradoxically, many felt at the same time that she was non-threatening as she could be placed in the role of ‘cared for’, and perceived as quite passive.

When one’s eyes are closed, different rules for negotiating space apply, the most common one being to use the sense of touch to reach out to others and locate them in

space. A ‘collision’ which occurred in the first workshop, probably did so because the participants were unused to the rules of non-visual spatial interaction. Jane, ‘feeling the world through her feet’ was very rarely involved in collisions. Goffman’s (1972) concept of the ‘*umwelt*’ is useful here, in that he defines it as ‘the space around the individual in which alarms can be discerned. In this respect the *umwelt* is simultaneously constituted through the perceptual field of the agent and her (body-based) vulnerability (i.e. what she can see that might injure her)’ (Crossley 1995b:140). In this exercise, I suggest, the people with the instruments created an audio-*umwelt*, around the participants, as their visual *umwelt* had been temporarily shut off.

This exercise was repeated in the second and third workshops, but with an alteration in that the group was not split in half. The whole group explored the space at the same time, with Charles playing percussion instruments, and Entelechy’s facilitators keeping watch over the group, making sure that they did not crash into things. During the second workshop, feelings about the exercise were again discussed. The issue of reorienting themselves in space without a visual framework recurred. Some participants explained how they felt when meeting someone in a purely tactile way, without the usual visual clues. For example, one participant said ‘My hand met another ... it felt like a real encounter. I didn’t know who I was engaging with, and I wanted to open my eyes. It took me a while to realise that that was it, that was the encounter ... It was more equal without names.’ It was mentioned that there was a ‘gut instinct’ which informed one more about the ‘real’ person before they spoke, what Goffman (1990) refers to as ‘personal front’, and that the status of the person being encountered did not seem to matter when visual cues were removed. Some of the participants were aware

that they were being watched by Entelechy members facilitating the exercise, which made them feel quite self conscious. As one participant suggested, 'I had a strong sense that someone was watching me ... I usually explore visually, to explore using my other senses felt like I was being exposed in public'. However, others were completely unaware, entering into a different state of being: 'I sat in the sun ... moved with my body in ways I wouldn't with others looking at me'; and 'It was liberating. It didn't occur to me that people had their eyes open guiding us'. The exercise gave some people what they felt was an insight into what it was like to be visually impaired, like many of their 'clients'. One woman said, 'With my eyes shut, the noise was much more intense ... that's what it's like for clients'. Another participant noted how their whole experience of the world changed when visual perception was removed: 'I explored the piano which was smooth and cool. I wouldn't usually have touched it'. Interestingly, one woman commented that when her visual senses were shut off, she felt a dissociation of hers and other participants' body parts, 'someone guided me with their foot. I didn't think about it until later, "foot!"'. Others reinforced boundaries around which body parts were made accessible to others. One woman said, 'The palms of my hands are very personal ... I put my foot out to test the space rather than my hands'.

According to Rebecca, this exercise recreated some of the experiences that are involved in Ambient Jam and The Diamond group, while working alongside people with profound and multiple disabilities, such as a feeling of physical and emotional release; having creative conversations; and experiencing a 'sublime emotional ambience'. Again, people with profound and multiple disabilities were being attributed with a certain level of 'authenticity' by Entelechy facilitators, representing 'genuine' emotions without the

trappings of the culture in which they were (tentatively) embedded. Rebecca said that the quality of doing nothing in particular, and letting things arise was important, creating a sense of timelessness. An atmosphere can be created, she said, where rather than doing a movement 'to' someone they choose to move because of the atmosphere.

a) 'Touch'

In the West, sight is the primary sense, and metaphors alluding to sight crop up in general discourse, for example 'I see' is commonly used as a synonym for 'I understand'. As has been shown, much of Entelechy's work is done through the medium of touch. In the BTW training, the issue of touch was constantly raised and referred to. 'Touch' implies intimacy in English culture, and, as Lawler (1991) has shown, carers have a difficult line to tread while caring for an ill or disabled person since physical intimacy is often required to carry out routine tasks in maintaining the 'client's' body (what Lawler refers to as 'instrumental' touch). At the same time, 'expressive' touch (Lawler 1991), which is spontaneous or affective, is discouraged. Intimacy, both physical and emotional, in the London boroughs where I carried out my research, was strongly discouraged in service culture. This was partly because health

and social services wanted to see relationships in a 'professional' and contractual way⁸⁷. Additionally, such adults were seen as 'vulnerable', and measures restricting intimacy are put in place to help prevent sexual or physical abuse. This had the unfortunate consequence that many people with learning disabilities, especially those who had physical disabilities as well, might rarely experience touch outside of an alienating contractual relationship, due to the fact that the only people they interact with are carers who keep a 'professional' distance.

Anxiety over touch was reflected in the behaviour of BTW participants, although this obviously varied according to socio-cultural background, gender, and 'personality'. After each of the workshops, participants were asked by Entelechy to feedback on open structured questionnaires how they felt about the training. Twenty seven people completed the questionnaires out of a total of thirty two attending the workshops. One of the most frequently occurring themes was anxiety or issues surrounding 'touch'. Out of the first group, in November 1997, 57% raised the issue of touch; in the second group in March 1998 the figure was 50%; and in the third in March 1999, the figure was 22%. The decrease in frequency of anxieties about 'touch' could have been due to the fact that, as the workshops developed over time, the Entelechy facilitators became more skilled at putting people at their ease around the issue of intimate bodily contact. Additionally, the third group was the smallest, with only eight participants, and several people commented on how a small group was more intimate and put them at their ease, whereas people in the largest group, group two, commented on how being in a group of 13, inhibited them. Anxieties about touch centred around several themes, including

⁸⁷ As is illustrated by the current rhetoric of 'service user' and 'service provider'.

sexuality, being physically intimate with ‘strangers’, and issues of power and aggression, as the following quotes by some of the participants illustrate:

‘Touching complete strangers was difficult. I had uncertainties around their reactions.’

‘I found it most challenging immediately having to be involved in touching people I do not know... it’s not a usual experience and I didn’t feel safe at first’,

‘I did not enjoy being “plunged in” to the touching/moving with others ... I would have preferred more time for myself in discovering other senses.’

‘I was OK with hands, and someone touched my feet which was OK. But other parts of my body were too intimate. There is an unwritten code that below shoulders and below hips is no go. I was worried that what I was touching was taboo.’

Discussion of ‘touch’ initiated debate among the workshop participants about issues concerning *normalisation*, and the notion of ‘age appropriateness’ (that is, the view that people, whatever their ability, should only engage in activities which reflect their stage in the life-course, and to do otherwise is humiliating and degrading). Some participants commented that touch between ‘clients’ and support staff was not encouraged where they worked. The thinking behind this was explained by a participant who worked for Mencap, who said, ‘if we encourage touch, and a person with learning disabilities goes and hugs a stranger in the street, they will be socially rejected.’ However, a few of the other participants, from different backgrounds, said that ‘hugs’ were exchanged between staff and ‘clients’. Some agreement was made around the proposition that: ‘You need to gauge when and how to touch. It’s very difficult’. Implicit in these comments is the idea that people with learning disabilities are unable to ‘judge’ for themselves when, and when it is not, appropriate to touch another person physically, and that this has to be policed and reinforced by outside agencies. Rebecca remarked on the case of one man in Ambient Jam, whom it had taken five years to

accept being touched⁸⁸, 'he is very happy now and will usually participate in contact improvisation'. The implication here is that 'touch' per se is seen as a 'good thing' and that cultural and emotional resistances to touch should be broken down when working with people with profound and multiple disabilities, most of whom cannot communicate verbally. Evidently, several contradictory views on the subject of touch were held by those who were present at the workshop. The utilisation of *normalisation* as the blueprint for prescribed behaviour of those who are deemed incompetent was in conflict with Entelechy's agenda of creating a liminoid space where touch could be experimented with.

Some workshop participants pointed out that touch could evoke strong emotions and care must be taken to avoid adverse reactions. The issue of sexual violence was raised, with one participant saying, 'some people may have a big problem in this area, for example, trying to come to terms with a recent attack or rape. They may not want to be touched'. Another participant said that she found the most difficult thing in the workshop was being in close contact with members of the opposite sex, as she felt physically vulnerable. However, there was a much higher ratio of women to men, with seven out of the total thirty-two participants being male, reflecting the gender distribution of workers in the 'caring' professions. Although workshop participants were from a fairly wide background, most were involved with statutory caring services.

Inhibitions arose because people were being asked to contravene the rules of 'normal' interaction, whereby: 'In going about their separate business, individuals - especially

⁸⁸ She was referring to Edward, described in the Ambient Jam section above.

strangers - are not allowed to do any physical injury to one another, to block the way of one another, to assault one another sexually, or to constitute a source of disease contagion' (Goffman 1963b:23). Touching strangers is the first step along the road towards these dangerous actions.

There is often an ambiguity around what is intended when someone touches someone else, and there may be a difference between the intention of the 'toucher' and the response of the recipient. It was discussed that 'touch' need not be 'taboo', but that it must be approached sensitively when working with 'vulnerable' clients, for whom 'touch' may trigger memories of abuse and other difficult memories and emotions.

People with profound and multiple disabilities are often perceived as being devoid of sexuality, and attributed a childlike androgyny. It seems to get overlooked, or side-stepped, in services that they do often get sexually aroused during physical contact with others, and little or no provision is made for this except to remove the individual concerned from the group. One female participant said: 'You can't just bring emotions out and not deal with them', which highlights directly the difficult line Entelechy was treading between 'art' and 'therapy'. David Slater said that emotions were often locked into the body, and through creative work they were opened out and released, indicating Entelechy's work was in some way cathartic. This had the implication that Entelechy believed emotions were embodied, and could be accessed through exchanging touch with people who may not be able to communicate verbally.

b) Music

The musician, Charles Hayward, was invited to the BTW workshops to share his practice of how to make music with people who have learning disabilities and profound and multiple disabilities. He asserted that disabled people could produce mainstream sounds, ‘if you get into the aesthetic ... manipulate and change it ... it can enable people to be more part of society by doing that’. He said that people should try and move things forward towards inclusiveness: ‘The aesthetic will change because we want society to change ... our criteria of what is excellence changes’. Charles explained his approach to music making, saying to the group of BTW participants:

We are not dealing in composition, we are responding to the architecture ... listen to the humming of the heating system ... listen in a new way ... let the outside world in. Whale song, bird song and prisoners tapping on plumbing all give examples of ways of opening up communication with people who are non-verbal ... they often have a different sense of time ... it’s about listening to sounds ... accredit them with intent, respond to them with intent.

Charles suggested that orthodox rhythm is about having two legs, and that people with disabilities often walk in a different way, so their rhythm (i.e. ‘habitus’) is different. He commented that in music sessions with people with disabilities, tambourines were often being ‘slapped around’ and there was an emphasis on being happy. He felt that instead everyone should go into the ‘tragedy’ of their lives, and investigate that uncomfortableness.

In an interview with Charles Hayward in DAIL⁸⁹ magazine, he further elucidated the ideas behind his work with Entelechy and people with learning disabilities, in particular Ambient Jam. He was very much concerned with the 'intent' behind people's actions, and felt that improvisation was a good way of making music accessible to this group of people. He was critical, however, of some of Entelechy's art facilitators (whom he termed 'art workers' or 'creatives'), as he felt that they often imposed frameworks on to the improvisations. He argued that intervention, or what he termed 'manoeuvring' people, by the facilitators should be kept to a minimum:

If you use completely raw improvisation, with just a space, some instruments and some people (some of whom are also dancers or movement workers), then suddenly what was somebody's disability becomes a signal ... At this point you can either say, 'This person doesn't really mean that,' dismiss it and turn it into a happy, clappy thing, where you have to play 'proper music'; or you can do what I do - which I think the people I've been working with really respond to - which is to say 'OK, you intend that signal, maybe as much as I intend a signal.'

Charles Hayward 2000:4

He explained how his work with profoundly disabled people was based on an understanding that 'intelligence comes from different parts of the body' (ibid.) which allowed communication on a non-verbal level, through music, as a kind of 'supra language or meta-language' (ibid.).

⁸⁹ DAIL is the Disability Arts in London magazine.

In the first BTW workshop Charles demonstrated how to use soundbeams⁹⁰ and samplers. He talked about how it was possible to work with someone who was making non-verbal sounds, and could not use conventional language, by reaffirming and giving shape to the encounter through using samplers, which echoed and reflected sounds which the person made. Charles then told the group about Ted, an elderly man who was blind and partially deaf, and had moderate learning disabilities (Ted died during the period of my research). He commented on how moved he was when he felt that Ted started to be able to 'listen' to the music: 'he brought his hand near to the keyboard, but brought it away again as he realised it was the wrong time to play'. Charles felt that Ted had 'intent' when he was playing on the keyboard, and had become a competent musician over time. However, Charles noted that some other professionals saw his progress from different angles; for example, a physiotherapist watching Ted play was more impressed by the fact that he was using his left hand, than by the music he was producing.

The BTW training workshops represented an attempt to open up discussion around different practices of working with people with learning disabilities in a creative way, aiming to give space to dialogue between the statutory sector and specific parts of the voluntary sector (including artists). Resistance from statutory services towards the type of work which Entelechy engaged in revolved around issues such as physical intimacy, choice, and *normalisation* policies. The participants attending the workshops, were, on

⁹⁰ Soundbeams are electrical instruments which pick up movements and vibrations and turn them into sounds. They are widely used with people who are disabled as the slightest movement can produce a sound giving the disabled person, who may have very limited movement, a sense of agency: 'Through Soundbeam there are opportunities for communication and creative expression that can enable people

the whole, open to new practices and different ways of relating to and communicating with people with learning disabilities. All the workshops mentioned in this chapter aimed to create forums where bodily 'habitus' could be explored, challenging the borderline between 'practice' and 'performance'. Their effectiveness in making the quotidian meaningful is debatable, as is the impact of 'framing' moments of encounters as 'performance' and attributing intent. However, a new aesthetic can be seen to have developed in Entelechy's practice, which both cordons off and incorporates alternative views of 'habitus'. At base, this 'new aesthetic' revolves around 'tuning in' to what they believe is another person's consciousness, through the body. It seems to be the case that Entelechy believed that the people with learning disabilities with whom they worked did indeed use movement (and sounds) to convey emotion, opening up a communication channel, rather than as an invocation of the emotion in their dance partner or 'audience'. The displacement of audience/performer dialectics can be seen, therefore, as a major strategy in the creation of this new aesthetic.

The next chapter explores some of Entelechy's work with people who have 'lower support needs' (i.e. they are more physically and intellectually able than most of the people involved in Ambient Jam and The Diamond group described above). Many of these people were able to articulate verbally their needs and wants, which raises new issues in their involvement in 'performance'. The potential for the arts (in particular performance) as a locus for sub-cultural resistance to the dominant culture of day centres is examined.

with profound and multiple disabilities to be creators rather than just consumers of music' (Sanderson 1995: 256).

Chapter Six

Subversion and the ‘inner idiot’: protest and conformity in day centres and the drama group ‘Weaver’

i) Introduction

In this chapter I concentrate on data collected in two day centres for people with learning disabilities. In particular I focus on a workshop run by Entelechy in one of these centres, entitled ‘*Weaver*’, a drama and creative arts group for people with ‘low support needs’, so defined in that they were categorised as fairly ‘able’: most communicated verbally and many were physically mobile. The majority of the group members were relatively young (mostly aged between 20 and 50)⁹¹. This was perhaps the reason why several of the Weaver members lived with their families, and most had never been institutionalised. This may also have been due to their comparatively high abilities which perhaps made it easier for them to stay in *the community* with kin support, or it may have been largely coincidence. The data referred to in this chapter was collected in ‘institutional’ environments (statutory service day centres), which were only used by people with learning disabilities and those involved in their care. This background contrasts with that presented in most other chapters, where much of the fieldwork data was collected in somewhat more ‘neutral’ territory, or what could be termed *community settings*⁹².

⁹¹ See Appendix I for breakdown of membership of the group

⁹² It is debatable whether the day centers could be described as in *the community*, although they are officially described as ‘community services’.

I took part in the Weaver group for approximately 15 months. Participation in this group provided interesting observations, including the group members' use of subversive strategies for survival in a situation where resources and attention had to be competed for. Utilising the ideas of Scott (1985) who analysed everyday forms of peasant resistance in Malaysia, I look at these forms of subversion and resistance used by people with learning disabilities within the day centres, and how such behaviour is both pathologised and incorporated by those in control (namely paid care workers/social services). Subversive behaviour or 'deviancy' is re-phrased as 'challenging behaviour' within statutory services. At the same time, the ideology of *normalisation*, explored in Chapter 2, acts, I suggest, as a powerful mechanism for maintaining 'abnormality'. It is within these material and symbolic discourses of 'care' and 'control' that people with learning disabilities have to live out their daily lives. Concurrent with Scott's view of the behaviour of Malaysian peasants, resistance is not interpreted as futile, but as about a question of survival, making everyday living bearable. Unlike the old asylums, the day centres were not 'total institutions', although the people with whom this chapter is concerned spent most of their week days there. Like the 'secondary adjustments' (Goffman 1991) to institutional life made by Sam⁹³, described in chapter 7, similar attempts were made by the people with learning disabilities in Weaver to exert some control over their environment. The research presented here demonstrates that behaviour labelled as 'pathological' by the medical profession is often a powerful form of protest, meeting participants' needs. Cultural interventions by Entelechy's facilitating artists can be seen, in some instances, to aid in improving the lives of the learning disabled members. However, by providing a forum

⁹³ An elderly man involved in the Rediscovering Our Histories project, who had spent over 60

where ‘challenging behaviour’ was less heavily policed, the workshops could be seen to act almost as a safety valve, a carnivalesque outlet which allowed structures of power in the day centre to be maintained.

As discussed earlier in the thesis, the treatment and representation of people with learning disabilities is heavily influenced by discourses around the idea of ‘normality’. It is apparent that the label ‘learning disability’, more colloquially referred to as ‘mental handicap’ or ‘retardation’, acts as a metaphor for wider social and cultural deviance. This, I suggest, whether consciously or not, potentially acts to diminish the potency of ‘real’ subversion by people with learning disabilities.

Lars Von Trier’s 1998 film, *The Idiots*, provides a useful example of the metaphorical use of learning disability as ‘deviancy’. This film has been heavily criticised by some members of the disability rights movement, who have found its portrayal of ‘mental handicap’ offensive. The film centres around a group of young Danish people who set up a commune, and regularly go out on trips into a local middle class neighbourhood of Copenhagen ‘spazzing’, that is, pretending ‘as if’ they had learning disabilities. Their aim is to subvert the norms of bourgeois society, and its hypocrisy in the way it treats diversity. They tried to do this through role playing scenes of anarchic behaviour, imitating how they believe people with learning disabilities behave. In this way, learning disability is used as a metaphor for rebellion.

years in Darenth Park Hospital.

The film's maker, Von Trier, believes that everyone has an 'inner idiot', a notion which he revealed in a television interview last year⁹⁴. The characters in the film are trying to get in touch with this facet within themselves. This 'inner idiot', Von Trier argued, is close to the idea of an 'inner child' but deeper down, a 'smiling illogical idiot', close to the heart and soul. This idea bears strong similarities to the Anthroposophical view of 'mental handicap' (people with learning disabilities are considered closer to the angels⁹⁵), which in turn is based on a mixture of Folk and Judeo-Christian beliefs.⁹⁶

Some disability rights activists have been upset by the implication of Von Trier's film that learning disabled people behave offensively or dangerously most of the time. Evidently this is not the case. However, as is true of the general population, some of them do, some of the time. The film also brings to light the very arbitrary social processes of labelling 'deviancy', and how 'incompetence' is constructed through social, cultural and historical discourse.

The behaviour of people with learning disabilities is, in general, much more heavily scrutinised and watched than that of the rest of the population⁹⁷. They have been labelled as 'incompetent', largely on the basis of observed 'abnormal' behaviour and/or development. Much of their time is spent in day centres and group homes where they are constantly supervised, and where 'abnormal' behaviour can be further observed and documented. Such supervision in and of itself is oppressive, but combined with the

⁹⁴ He was interviewed in a documentary 'Playing the Fool', on network television's Channel Four, shown on 19th August 2000, directly preceding a screening of *The Idiots*.

⁹⁵ See Nash 1997.

⁹⁶ Explored in Chapter Two.

hegemonic power structures in such institutions (and most should be considered as ‘institutions’ even though they are located in the *community*), in which the non-disabled minority control the learning disabled majority, an extremely oppressive culture develops, often all the more so when couched within an ideology of benevolence.

Subversive or difficult behaviour, labelled within services as ‘challenging behaviour’, includes aggression, self-injury, destructiveness, non-compliance, and public masturbation. In relation to ‘challenging sexual behaviour’, which, I suggest, can be applied equally to all ‘challenging behaviour’, Cambridge and Mellan assert that:

In service environments, the informal codes relating to particular sexual behaviour or the sexual norms within particular cultures or communities are usually absent, thus increasing the probability that some more unusual sexual behaviours will be labelled as challenging or pathological.

P. Cambridge & B. Mellan 2000: 295

Such behaviour is further brought into focus by the fact that people with learning disabilities in service environments usually lack privacy and boundaries, (although, as Cambridge and Mellan point out, privacy is hard to define in shared service environments). The labelling of such behaviour as ‘challenging’, and attempts at ‘incorporation’ within the system, aimed, I suggest, to reduce the potency of such acts.

The engagement of people with learning disabilities in ‘the arts’, specifically ‘performance’, is often seen as a contravention of *normalisation*: that is it is felt that disabled people should not make a ‘spectacle’ of themselves. The Weaver workshops were potential areas of conflict, where differing ideologies met: the avant-garde liberal

⁹⁷ A point also raised in Davies and Jenkins research report (unpublished) on transitions to adulthood of young people who have learning difficulties, in Wales.

aesthetics of Entelechy versus the behavioural/interactionist day centre policies. The group upon which such ideas were played out, namely people with learning disabilities, had relatively little material power, but, as I hope to show, through participation in the Weaver workshops, was often enabled to convey some degree of symbolic power.

ii) Fieldwork context

Observations were made in two inner-city local authority day centres: The Diamond, and The Seagull⁹⁸. At the beginning of my fieldwork, Entelechy's offices were based at The Diamond Day Centre. There was a reception area at the front of the building where the day centre office was based, and access to and from the building was controlled. The door to the office was locked with a code printed next to it, the assumption being that people using the day centre would not understand that the code matched the lock (an assumption which proved to be incorrect). The day centre office was seen by the care staff as an area of calm, where some semblance of 'normality' could occur.

However the sanctity of this office was frequently threatened: on one occasion I went there to use the photocopier, and while photocopying I was thrown against the window by a woman whom, I was later told, had a 'dual diagnosis' of paranoid schizophrenia and learning disabilities. The staff told me that she was hallucinating, which apparently caused her to attack me. Interestingly, the incident was quickly glossed over by the day centre staff. To admit disruption was perhaps to concede that the people with learning disabilities had agency. The incorporation of 'challenging behaviour' into the ebb and flow of office life seemed to be an attempt to try to make it appear mundane, making it

less disruptive and threatening to deal with. However, this strategy did not seem totally effective in practice. There was a very high turnover of day centre staff, particularly in the 'challenging needs' unit, where physical attacks were apparently a daily occurrence. 'Burn-out' rates were evidently very high. Frequently the centres were staffed by agency workers, drafted in on a temporary basis, who were unfamiliar with day centre practices and ideologies. This gave greater opportunity for the resistances and acts of defiance expressed by the people with learning disabilities to be effective.

Consequently, day centres for people with learning disabilities are places where rules and norms of everyday life are both continually reinforced and ignored, which can be very confusing for all concerned. This ambiguity over what is and is not acceptable behaviour throws into relief what the actual rules of interaction are. Taking Goffman's (1963b) axis of 'tight' to 'loose' social situations, life in the day centre rests somewhere in the middle of this continuum. The situation was 'loose' in that behaviour such as incontinence and dribbling were tolerated, whereas it was 'tight' in that violence, masturbatory activity and sexual activity were heavily policed (even if staff tried to make it appear as if it were not, in order to try and reduce the impact of such acts), with 'offenders' being removed from communal areas.

Some people with learning disabilities challenge what Elias (1978) termed 'the civilising process', by urinating, defecating, dribbling and spitting at random. Elias describes a lengthy historical process occurring in the West, spanning several centuries, during which moral and symbolic attitudes towards the body and bodily behaviour changed.

⁹⁸ Pseudonyms

Over time, bodily functions were increasingly hidden ‘behind the scenes’, in relation to changing moral attitudes, rather than for hygienic reasons. He asserts that there has been a shift from ‘*external constraints*’ to ‘*internal restraints*’ over time in Europe in permissible bodily behaviour. This has been incorporated in the socialisation process from child to adult. As stated earlier, people with learning disabilities have an ambiguous status, hovering between childhood and adulthood, depending on context; therefore the behaviour expected of them is also ambiguous. For example, during a dance session, one woman took my hand and wiped her saliva all over her face with it. In the day centres, when people had colds, they would often wipe their noses on their sleeves. I saw one young man pick his acne spots until they bled, wiping the blood across his face and creating deep fissures in his skin. In the day centre, some wheelchair users sat on clearly visible incontinence pads, which lined their chairs. Changing incontinence pads, and ‘toileting’ took up a lot of the day centre staff’s time. Often toilet doors were left slightly ajar, while people used them or were being changed by staff. Noises such as screaming and bodily functions that came from the cubicles were clearly audible to those in the vicinity. Therefore, the day centre users had a different sense of what was and was not acceptable bodily behaviour compared to a person who lived outside such an environment. Bodily boundaries were very open and fluid (often literally).

The day centre acted as a container for such activity, which would not be tolerated in a more public place. However, when out in public, such as visiting the market or using the local community arts centre, attempts were made by day centre workers to restrict or hide such activity such as by verbally chastising the offender, or taking them to a

toilet where they could be screened off from public view. It was my understanding that the worst 'offenders' were rarely taken out of the building by the day centre staff.

The Diamond day centre was in the middle of a council estate, bordering onto a railway track. Nearby was an arts centre, where some of Entelechy's workshops were held, and to where Entelechy moved shortly before the end of my fieldwork. Market stalls and shops surrounded the arts centre, which were frequented by people from the day centre. People with disabilities were therefore a common sight in this area. This led to a certain amount of what Goffman has termed 'sheltering' occurring in the immediate vicinity of the day centre. Speaking in respect of mental patients, Goffman states: 'the service shops which are sometimes found in the immediate neighbourhood of mental hospitals may become places with high tolerance for psychotic behaviour' (1963a:69). However, he notes that 'familiarity need not reduce contempt' (Ibid:70). Staff from the day centre frequently accompanied the 'service users' into the market, thus exposing them to 'normal' interactions, instead of a sheltered environment. In line with Goffman's proposition that: 'in so far as others judge the individual socially by the company he is seen in, for him to be brought into engagement with another is to be placed in the position of being socially identified as the other is identified' (1963a:104), I found that care staff frequently walked several paces in front of or behind their charges, or pushed a wheelchair, which could be propelled by its user alone, in order to show to the public that they were not 'learning disabled'. They were showing themselves to be in the role of a 'carer', a higher status than being seen as disabled, although still connected to this devalued personhood. People with learning disabilities who frequented the market area

were often treated as non-persons in that they were walked past and looked at, i.e. to use Goffman's terms, as 'physical objects' rather than 'social objects' (Goffman 1963a).

The workshop, Weaver, was held at The Seagull Centre, run by Entelechy on a peripatetic basis. The aim of the group was to work creatively together, and to produce performances and installations. Like The Diamond Centre, The Seagull also had a very institutional feel. Above the door was an old sign saying '*Seagull Adult Training Centre*', a relic from previous decades when emphasis was placed on 'training' people with learning disabilities, attempting to rehabilitate them and imbue them with a sort of work ethic, although 'real' jobs were rarely achieved. In the 1990s, the focus changed to a wider range of activities for people with learning disabilities, incorporating leisure, education and training. Such day centres bridge an uneasy gap between life in the old asylums and life in *the community*. They are relatively cost effective in that they can provide non-residential surveillance for large groups of people with learning disabilities, with fairly low staff ratios. What happens to the 'service users' 'after hours' is usually beyond their remit.

The Weaver group took place in the centre's dining hall for two hours each Tuesday morning. The tables and chairs had to be moved to the sides of the room to create a space for the group to work in. Bits of food from the previous day were stuck to the wooden floor, which did not make an ideal surface on which to work. There were constant interruptions from other day centre users and catering staff who wandered in and out of the hall during the sessions. Strategies for reinforcing the boundaries of the group were therefore employed, such as closing the dining room doors. However, this

was not very successful and the group remained permeable. All groups within these day centres appeared subject to disruption, and this reflected the low status of the activities which were performed within them, with both staff and 'clients' wandering in and out at random. Entelechy disapproved of this culture as they felt it reinforced the negative stereotypes of people with disabilities, in the sense that their activities were not of equal value to those of non-disabled people, who could expect to rehearse and perform without interruption.

The group was run by one or two performance artists from Entelechy. On average, there were about eight people with learning disabilities who attended the group each week. In addition, a worker from the day centre attended, and occasionally volunteers and occupational therapy students on placement at the day centre. Weaver was run along the lines of a modern dance and drama group, although geared towards people with learning disabilities. The group followed a similar pattern in each session. There would be a warm up, followed by improvisations, games, massage, or movement and dance work. The session would end with a 'cool down', usually taking the form of relaxation exercises. I joined in all the activities, arriving and leaving with Entelechy.

iii) Relationships and intimacy

The Weaver group provided the day centre users with an opportunity for socialising, more so than in the rest of the day centre where social interaction was more tightly regulated. Intimacy was actually encouraged in the group through activities such as massage and contact improvisation. Mostly, Entelechy worked with people with learning disabilities only for short periods of time. This meant that there was greater

tolerance towards difficult or 'bizarre' behaviour in the sessions, which sometimes led to conflicts between day centre staff and Entelechy artists as to what was acceptable.

The treatment of the sexuality⁹⁹ of people with learning disabilities within service provision raises many complex issues around consent, power and abuse. Negotiation of policies which respect the rights of people with learning disabilities, at the same time as recognising the importance of 'safer sex' and abuse issues, has proved very challenging for many service providers and is an area of ongoing debate. As highlighted in previous chapters, within statutory services policies are in place which strongly discourage intimacy, specifically touch. This is often a response to the need to protect staff from allegations of abuse, but also results from interpretations of the ideas behind *normalisation*. Such an environment makes it very hard for some people with learning disabilities to understand what is 'appropriate' touch and how to express emotions.

This has resulted in:

Widespread deprivation of love, affection and physical closeness within formal support regimes, with huge professional distance between service users and support staff. Displays of affection are likely to have been ignored or discouraged with the widespread invisibility of affection and inter-dependency within learning disability services. Services need to build new models and interpretations of Normalisation ... if such barriers are to be crossed.

Cambridge & Mellan 2000:306

The intimate situations which involvement in groups such as Weaver produce is provocative, and questions blanket policies. Massage was clearly one such catalyst for intimate exploration which Entelechy allowed, and it was frequently used in the Weaver group. Entelechy allowed exploration of the social boundaries around people with learning disabilities' sexuality, but did not let the situation go beyond their active

control. This may, perhaps, have provoked more frustration on behalf of these people, although sexuality was not treated as a taboo area. This is one area of service provision which needs to be further addressed, and forums made available where issues around sexuality can be discussed by both staff and people with learning disabilities. The medium of the arts is one potential arena where this could be explored (e.g. through role play), but would be more useful if everyone connected to this issue was involved.

I accessed and experienced the Weaver group largely through interaction with one particular member, Gail, who is discussed as follows:-

iv) Gail

Gail, a 38 year old woman who regularly attended the group, was described as extremely 'challenging' by the day centre staff. It was felt that she needed individual 'support' in order to participate in Weaver. However, this was not provided by the day centre, so I was informally appointed (by Entelechy) to the role of 'containing' Gail, which was a very difficult position to maintain alongside that of being an impartial participant observer.

Gail was probably the least involved member of the group. She constantly subverted activities, usually through non-compliance. She always appeared to be heavily sedated and very tired. She had a reputation for biting and scratching staff, and on one occasion (which I did not witness) was reported to have taken a 'large chunk' out of a Seagull worker's arm at the start of a Weaver session. Gail enjoyed taking all of her clothes off,

⁹⁹ Further discussion of this important issue can be found in A.Craft (1994); McCarthy & Thompson (1995); and Cambridge & Mellan (2000).

and it was on one such an occasion that she lashed out at the day centre worker who was trying to prevent her from doing this.

In response to the latent anxiety raised by Gail's behaviour, I was required to 'police' her, and felt under scrutiny by those running the group if I did not. This action can be seen as in contradiction to Entelechy's usual stance towards 'challenging behaviour'. I suggest that this was because the Entelechy 'apprentice' facilitator (Peter) who ran the group during the first few months of my fieldwork, was fairly inexperienced, and felt that there was a real danger of violence. Additionally, the Weaver group could be threatened with closure if they could not be seen as containing such behaviour, as they were funded through The Seagull Day Centre. I tried to treat Gail in as neutral a way as possible, only discouraging her behaviour when her actions would severely disrupt the group, e.g. when she stripped off all her clothes. Inevitably, though, my presence impacted on her behaviour, and I found it difficult to reconcile this with my role as an anthropologist. Gail did not interact easily with other members of the group, and her relationship with me dominated her involvement in the sessions. Over time, I became Gail's advocate during the sessions, helping her to engage in activities and form some connection to other members of the group. Over the weeks, Gail became very friendly with me, holding my hand and wanting to be physically close to me during most of the sessions.

Gail lived in a large hostel, with several other people with learning disabilities, close to the day centre. I visited her home once and found it to be very institutionalised with bare corridors and utility furniture. She had spent the majority of her life in a large

'mental handicap' hospital, and was now living in *the community*. It is debatable as to how integrated into *the community* she actually was. The only observable difference between being in a hospital and living in *the community* for Gail appeared to be the fact that she had to walk down a tree-lined residential street to get to and from the day centre. There were plans to close her hostel down and move the residents into smaller units of accommodation, as was recommended in a recent inspection. She relished her 'day off' from the day centre, where she could sit at home in her own room doing whatever she felt like. Gail especially enjoyed being massaged during the Weaver sessions, and it was her enjoyment of the massage in these sessions that prompted her hostel to employ a massage therapist for her. This was an example, therefore, of how involvement in Entelechy improved one area of Gail's life, largely through Entelechy co-ordinating information about her needs and desires to all those involved in her care.

Gail's institutional environment was reflected in her behaviour. She referred to care staff and members of Entelechy (and sometimes myself) as 'nurse'. She was able to distinguish who had learning disabilities from those who did not, (which even those labelled as profoundly disabled seemed to be able to do in my study). She constantly sought approval for her actions, and asked me to report to other 'nurses' (day centre staff) that she had been 'good'. She was aware that she was constantly under surveillance, and seemed fearful of reproach. It was likely that in the 'mental handicap' hospitals she was frequently punished for aberrant behaviour. This would probably have taken the form of 'behaviour modification', which involved a system of rewards and punishments. However, despite seeking approval and being very wary of authority, Gail still persisted in trying to subvert it through anarchic behaviour such as violence

towards others or public nudity. She seemed very aware that removing her clothes in front of others provoked strong reactions, such as masturbatory activity from male members of the group, and that this would result in the activity/group descending into chaos while the care worker/s tried to regain control of the situation. Another very powerful device which Gail used was speaking in the third person about herself, as if she was a critical care worker or nurse from her past. For example, in response to being asked to join in an activity in Weaver, she once replied, 'she's got shit on her hands ... she's dirtied herself'. On another occasion, she said to the group leader 'do you know what she's done? She put her pad in the bin', (referring, I assumed, to a sanitary pad). Answering requests to join in activities with statements about the taboo subject of personal hygiene was very effective in demonstrating that she did not want to join in, and had a much greater effect than if she had just said 'no'.

Gail usually wore make-up, and had a short neat hair cut. She normally wore dresses, and carried a handbag in which there was sometimes a book of symbols and words¹⁰⁰. She frequently referred to her hair, saying that she wanted to dye it pink, or wash it; speaking in short phrases such as 'wash hair'. Gail often complained of feeling physically unwell, saying she felt 'sick'. She usually contradicted herself throughout the session. Initially, if asked to join in, she would say 'want to rest' or 'want to go home', 'want to go to bed'. Later in the session she usually became more animated and would tell me or whoever she was near that she wanted to wash her hair, or say the name of the day of the week. She often said at the end of the session 'I enjoyed it', as if this was

¹⁰⁰ It was unclear as to whether Gail chose to present herself like this, or whether staff at her care home imposed their view of what she should look like, along the lines of *normalisation*, resulting, perhaps,

expected of her in order to avoid punishment. Gail had a habit of describing what she was going to do before she did it. For example, she would say that she was going to take her shoes and socks off, then she did so, almost as if she were asking permission or challenging someone to stop her. When Gail was about to strip naked, she would say that she was too hot, and flap her clothes up and down, looking at a person in authority in the group with a sideways glance, once again challenging them to stop her.

Gail often seemed to drift into trance-like states. On one of these occasions, she touched her chest, pointed to her genitals, and touched her knees. She did this action several times in a rhythmic way. I asked her if she was all right, but she didn't seem to hear me. A day centre worker on the other side of the room noticed her behaviour. He signed to her 'toilet', and asked her if she wanted to go. I repeated this to her in words. By then, she had come out of her trance and said 'no', and was a bit giggly. She talked to me about washing her hair, and got her brush out of her bag and brushed her hair. She talked again about dying it pink, as in a poem she had previously written in the group, and mentioned that she was going to a social club that night, saying 'Day off ... tomorrow'.

Such trance states are usually pathologised as 'psychotic' episodes. I suggest, however, rather than being psychotic, it was a learned cultural response. Within such a state, Gail breached taboos such as touching her genitals. The support worker's immediate response to her behaviour was that she needed the toilet (that is he felt she needed to be

in gender stereotyping. Trousers would have been a much more practical option for joining in drama activities.

sequestered), and that her behaviour was due to lack of inhibition due to her pathological state rather than an expression of defiance (i.e. the belief that she does not exhibit intent). Gail had very few options open to her for being subversive, in that she had very limited access to resources other than the use of her own body, which is an extremely powerful medium. Throughout their lives, people like Gail have been treated with very little respect and attributed very little agency. 'Dirty protests' such as fouling in public, spitting and bodily exhibitionism are, to use Scott's term, their 'weapons of the weak'. Similarly, in Boddy's (1989) description of the *Zar* cult in northern Sudan, women in possession states can get respite from their subordinate status through assuming roles which would normally be taboo. I am not suggesting that Gail can always control entering into a trance, but I assert that by entering into a trance-like state she is able to challenge the behavioural norms imposed upon her. Gail's behaviour can be compared to the Malay condition of *latah*, in which a person responds to being startled by swearing, mimicking (echolalia) and automatic obedience to instructions. In *latah*, as described by Winzeler (1995), the condition seldom involves neurobiological pathology, and 'Once it was established, cultural learning, expectation, and individual need and social use appear to be adequate explanation for the existence of *latah*' (Winzeler 1995:136)¹⁰¹. Gail's trance states and echolalia may have their origin in neurobiological pathology, but she has found that it is a useful response, as have other 'clients' in the culture of day services. She was able to use this response, in a similar way to spirit possession and *latah*, in order to assert herself and combat her social marginality. As Winzeler, following Lewis (1986, 1989), asserts, 'possession can

¹⁰¹ R.C. Simons (1996), however, gives greater emphasis to the role of neurophysiology in *latah*.

absolve the affected person of responsibility for behaviour that might not otherwise be tolerated' (1995: 135).

Other group members often employed linguistic strategies as a form of subversion. For example, during almost every session, Sonia¹⁰², a middle-aged woman who had Down's Syndrome, went up to each of the people running Weaver, saying and signing that her 'mum' was dead and that 'Bob' was ill. The person to whom she directed these statements would reply in sign and speech that they were 'sorry'. Sonia got so used to people answering her this way, that she started to imitate them and say 'sorry' in response to her own statements. She said it so frequently and with such predictability, that the tragedy inherent in her words seemed to diminish. She was performing the bereaved daughter, with complete awareness that this role usually elicits sympathy and attention, and has a much more powerful effect than simply saying 'hello'.

Attempts were made by social services to sanitise and normalise Sonia's obsession with death and illness. They provided her with individual psychotherapy sessions, which they hoped would act as a receptacle for these feelings. Her everyday use of her mother's death in speech was evidently seen as dangerous and needing to be contained. It was disruptive to normal codes of conduct to evoke such emotions at will, partly because they lose their power for 'genuine' cases of bereavement and sickness, but also because it was felt to be offensive to continually raise subjects such as death and disease in conversation.

v) Poetry

Sometimes the Entelechy artists facilitated the expression of such speech patterns as Gail's and Sonia's, which had often been interpreted as pathological, making them into poetry. This had the intent of being subversive (on the part of Entelechy) in that it gave value to non-normative modes of communicating, rather than trying to 'correct' or normalise them. This has continuities with the approaches taken in the ROH project, discussed in the next chapter, in that 'coherence' of narrative was not seen as the only and best way of conveying narrative/lived experience, and reflects ideas seen in surrealist movements and post-modernism:

Surrealism sought to let everyone explore its liberating processes, taking a cue from the saying of the poet Isidore Ducasse: 'Poetry should be made by all'.

M.Gale 1997:8

One of the last projects that Weaver worked on while I was engaged with them was a poetry project. This was the second time that Weaver had worked on poetry. The first time was before I commenced my field work, but I was able to look at some of the poems which had been produced. The poems were written down by Rebecca Swift, but they were dictated by the members of the group with learning disabilities. In some cases, with the less articulate members of the group, words or phrases which they said were written down and 'framed as' poetry.

Almost a year after first working on poems, many members of the group remembered their poems verbatim. For example Gail, whose first poem was made up of words and phrases which she commonly used, was able to repeat her poem when prompted:

¹⁰² Sonia was mentioned in Chapter 4 in connection with the BTW training workshops.

Bath day off lay in
 wash my hair
 shampoo colour my hair
 get up in the morning
 Friday morning lay in bed and sleep
 You make the tea
 In my hand bag
 In my hand bag
 I'm going to colour my hair green
 No pink

Gail obviously felt a sense of ownership over the poem, recognising her own style of talking encased within it. Gail's second poem, pieced together and written down by Rebecca, was created by linking words and phrases with her actions as she emptied out her handbag and described the clothes that she had on. Rebecca later encouraged Gail to learn the poem:

Look! New dress
 Bought it in a shop
 Look! Blue dress.
 Bought it in a shop. (cost £2)
 Have you got a new coat?
 Have you got a new shirt?
 Bought it in a shop (cost £2)
 Look! Wash my hair
 Look! Wash my hair
 Shampoo? Ain't got none.
 Shampoo? Ain't got none.
 Buy it in the shop
 Buy it in the shop

Jim, another Weaver member, was a thirty five year old man who had a diagnosis of autism and other learning disabilities. He frequently spoke in short phrases, usually repeating what he had just said. His first poem was mainly about his brother Liam, who had caused a lot of trouble and who was now 'in the pin' (in the pen, i.e. prison):

Are we going out tonite?
 Are we going out tonite?
 Mum's house got broken into
 I'm gonna tell Liam
 I'm gonna kick his door in
 Here, what you talking about?

Liam's not in.
 He's in the pin.
 I'm going to have to kick his door in
 He's done that and that and that and that
 He's not coming down tonight
 I'm not going to let him in.

Jim's second poem was also about his family, and current events that were going on for him:

I've got a jumper on
 I've got a jumper on

Mum's gonna work today
 Mum's gonna work today

Liam's not phoned back
 Liam's not phoned back

Are you going out tonight?
 Are you going out tonight?

-don't know - don't know
 -don't know - don't know

He's alright, Liam, now
 He's alright, Liam, now

He's gonna work
 He's gonna work

What are you doing tomorrow tomorrow?
 What are you doing tomorrow tomorrow?

Couldn't care less!
 Couldn't care less!

Jim listened closely to what people said and repeated words and phrases from overheard conversations. He often said the same phrase twice, which is reflected in the poems. It was very difficult, if not impossible, to hold a 'question and response' conversation with him. However, he seemed very aware of what was going on around him, and narrated his life in the third person. Rebecca encouraged the whole group to learn Jim's poem and repeat it as a chorus, which Jim appeared to greatly enjoy.

Both Jim's and Gail's poems take the form of non-sequential narratives, jumping about all over the place, giving snapshot glimpses into their thoughts and lives, like the 'automatic writing' of Dadaism¹⁰³. Some poems were on a more mundane level, dealing with immediate issues. For example Sonia talked about (in Makaton and words) her broken hearing aid, and this was 'framed as' a poem by Peter:

Ear hurts
hearing aid

tomorrow
tomorrow
doctor

hearing aid
Its broken

next week
hearing aid

next week
go home

Shaun was a 24 year old man who had Down's Syndrome. His two poems contrasted quite starkly. In the first, he talked about his family and his cultural roots, whereas in

¹⁰³ See Appendix X

the second, he had strung together a collection of words describing his weekend, which strongly evoked a picture of his life as mundane and repetitious:

1. My mum works in the kitchen
 My sisters live in Hong Kong
 - Carol and Anna
 I'd like to go to Hong Kong.
 - Never been
 Mum cooks Chinese food -
 Rice, chicken, fish, cabbage
 Mum's in Hong Kong
 coming back on Monday
2. At home Friday and Saturday. Saturday and Sunday.
 Channel Four racing, horse, tracksuit, helmet, glasses, boots – that's it.
 Horse racing, tracksuit, cowboy, BBC1, cartoon,
 Black Beauty, ITV – that's it.

Matthew, another member of the group who was diagnosed as autistic, created quite a surreal poem, which reflected his speech pattern and was fairly disjointed, pulling out random phrases and statements:

Like to work in Woolworth's
 and be in a show
 Go shopping in the saver centre
 go this way
 Buy bread, milk and eggs
 go with Lenny
 Sam's a keyworker
 Sam's having a baby
 Abul works here
 Wayne works here
 Harry works boxes

"Iain another question"
 "Matthew about clothes you are wearing?"
 "Clothes?"
 "Buy your own clothes?"
 "Like C&A. Go shopping with mum. Dress - up"
 "Dresses and skirts?"
 "Yeah!"
 "Matthew!!"

The last part of the poem takes the form of a conversation between Matthew and another member of the group who had Down's Syndrome, Iain. Matthew enjoyed cross-dressing, and Iain was teasing him about this¹⁰⁴. Iain was obviously aware that such behaviour was 'deviant', and in a playful way, was chastising Matthew for being 'different'. Research shows that staff may reinforce the idea that such behaviour is deviant:

Cross-dressing is regularly reported by support staff during sexuality training and is a sexual behaviour which generates considerable professional and management concern ... Cross-dressing confronts conventional attitudes about sex, gender and appearance, creating confusion about heterosexuality ... Considerable confusion between cross-dressing, trans-sexuality and homosexuality therefore frequently surfaces in staff teams, and such imprecision risks re-enforcing any confusion the man himself might hold in relation to his sex, gender, sexuality or sexual identity.

P. Cambridge & B. Mellan 2000: 296

Cross-dressing and other forms of experimentation with roles, however, were not discouraged by Entelechy in the Weaver (and other) groups. Iain knew that he himself was 'different' from most people, but wished to emphasise his 'normality' in comparison to Matthew. Iain often presented himself in the sessions as a 'macho-man', flexing his muscles and pretending to do martial arts. It seemed to be the case that in order to feel accepted, he had to 'perform' as if he were an extreme gender stereotype, to overcompensate for his 'differentness' by being more 'normal' than 'normal'. The ideology of *normalisation* reinforces stereotypical gender role behaviour, as people with disabilities are encouraged to adhere to cultural norms of both behaviour and dress, almost to the point of becoming caricatures of Western 'maleness' and 'femaleness'. Additionally, as Craft and Brown (1994) point out, gender inequalities are often reproduced in the power structure of the services in which people with disabilities

spend much of their lives. For example, care workers tend to be predominantly female, and managers male (although in the case of The Seagull centre, the manager was female). Such a situation would obviously impact on how people with learning disabilities see male and female roles. Atkinson and Walmsley (1995) assert that women's issues need to be directly addressed, otherwise 'the policies and practices generated by normalisation may replicate the gender divisions of the wider world' (1995:219). This approach encourages positive intervention in the lives of people with learning disabilities to prevent the reproduction of gender stereotypes within institutions such as day centres, and in *the community*. In practice, however, as my material shows, gender stereotyping goes on to a high degree, with 'clients' such as Gail being 'normalised' by her care workers by the application of make up, and the provision of a handbag (which was usually empty). Kerry, a young woman attending the Weaver group who had Down's syndrome, rejected the female role presented to her, and adopted the stance of a 'tom boy', copying much of Iain's behaviour. However, by performing 'macho-ness' she was still rigidly adhering to stereotypical gender roles, albeit that she was adopting a gender role which was opposite to her sex role. Behaviour such as 'cross-dressing' was discouraged in the day centre as a whole, as it was seen to be projecting an image that was not 'socially valued' and was therefore against the principles of *normalisation* (and was also threatening to many care workers' cultural beliefs).

¹⁰⁴ In the workshops, Matthew tried on the same wedding dress that had caused the controversy on the BTW workshop when Sonia wore it. The dress was a highly potent symbol, signifying heterosexual 'marriage', which was powerfully subverted when worn by members of the Weaver group.

The medium of poetry can be seen to work well with people with learning disabilities who use speech as their main means of communication, even if, as in the above cases, their language is non-sequential or erratic. It can sometimes be used as a medium to express 'deviant' feelings and behaviour, as noted above. Rebecca felt that the poetry worked on two levels:

Firstly, artistically ... very rich and strong material which relates directly to people's everyday experiences and aspirations ... and secondly, socially we found that the poems brought the group together. People were interested in each other's work as well as their own and so opened up to the whole group.

Atkinson and Williams (1990), writing about the creative expression of people with learning difficulties, argue for an examination of what is termed 'good art'. They see creativity as a route to self-expression, and a 'testimony to the human spirit's will to survive' (1990:110). Drawing on the experiences of an adult education teacher, they suggest that creative work does not demand the same amount of 'competency' as other areas of life, and that people who are used to 'failing' can build confidence through participation in the arts. I agree with this statement to an extent, but suggest that it perhaps under emphasises the skills which many people with learning disabilities do have in other areas of their lives, but which often only become apparent to 'normal' people when expressed through creative means. Rebecca drew attention to this process in the poetry, by saying that 'Matthew notices everything. They all do, but they get away with mucking about because we don't think they are capable of noticing what's going on'.

vi) Performance

Performances were sometimes developed around improvisations by the group. Rebecca, who ran Weaver in the latter part of my fieldwork, developed a performance based on a fairy tale. In the early stages of rehearsing, she made attempts to include the more disruptive members of the group by giving them space to do their own improvisations, which were not part of the narrative flow of the performance. For example, space was given to Gail to perform a short sketch where she took items from her handbag and showed them to the audience, reciting her second poem. However, as the term progressed and the performance was finalised, Gail was excluded from the action. The aim of Entelechy to involve everyone in the creative process regardless of their ability was, therefore, not entirely achieved. A coherent sequential narrative was given precedence over individual non-narrative improvisations. This contrasts with the performances and ‘happenings’ described in previous chapters, which, though not always ‘spontaneous’, veered away from traditional performance aesthetics involving sequential ‘acts’.

What had started off in rehearsals as a piece bearing similarities to a Dadaist performance, was being shaped into a conventional fairy tale/pantomime, which was more culturally normative. Interestingly, however, when such a performance took place in the day centre with other service users and staff present, people with learning disabilities took over the action and the result was fairly chaotic. Interventions by group leaders were made to try and steer the performance according to the pre-established narrative framework, but this was overridden. This was even more evident when the Weaver group performed to an audience mainly composed of their peers at a night-club

run for people with learning disabilities, where a sense of solidarity between audience and performer arose, moving the action in the direction of anarchy. It was this more than the content of the performance which impacted on the audience, as the following extract from my fieldnotes illustrates:

The following February, the group performed at the Beautiful Octopus Club. There was an audience of approximately three hundred people with and without learning disabilities. Rebecca and Phil (a day centre worker) organised the group, with Rebecca narrating and Phil taking part in the performance. The performance got quite a good reception, despite the action being all over the place, and several members of the cast getting lost in the audience. Members of Weaver were well known to much of the audience, as they attend the same day centres, and the audience seemed to derive pleasure from seeing their friends and acquaintances on stage.

In this particular performance, the actors with learning disabilities took over the action, thus promoting the idea that they do have some control over their environment and possess agency.

vii) Conclusion

In this chapter I have shown some of the strategies which people with learning disabilities adopt to subvert day centre life and the activities organised for them, and how this subversion is sometimes incorporated by Entelechy into aesthetic activity. The learning disabled members' strategies may not be particularly effective in bringing about change in their lives, but they do go some way towards making their presence felt and their wants and needs acknowledged. One such strategy was evidently the use of various linguistic devices, which are often pathologised as 'speech disorders' or attention seeking behaviour by the medical profession. For example, *echolalia*, the parrot-like echoing of speech, is, according to Frith, commonly found among autistic people (1989). Frith asserts that the most often repeated words and phrases are those

uttered directly *to* the autistic person. Such echolalia among my informants often occurred some time after they had originally heard the phrases. Frith argues that echoing is often ‘merely stereotyped behaviour, and does not stem from any communicative intent’ (1989: 123). My research, however, challenges this, as most of the echolalic speech which I came across during the Weaver group, and also in other areas of my research, was directed at the ‘normal’ people in charge of the activity. Therefore, I suggest, that rather than being a purely pathological condition, echolalia can also be seen as a learned cultural response to dealing with authority. My findings bear similarities to the example quoted by Czaplicka (1914) who recorded an incident of Transbaikal cavalymen who suddenly began repeating everything that their officer said, and the more he admonished them, the more they became echolalic. This incident has been compared to mass hysteria, which was not occurring in the context of the day centre. However, I suggest the day centre users often borrow linguistic practices from their peers, as a form of mimesis. Echolalia can also be seen as having a communicative function. For example, Jim, an autistic member of Weaver, tried to make sense of the difficult situation in his home by repeating phrases which his family had said to him. These statements were not said randomly, but in response to questions such as ‘how are you?’, or when the attention was focused on him in a warm up exercise or improvisation. Gail repeated words and phrases which had been said to her, which she obviously found insulting or distressing. She talked about herself in the third person, using profanities such as ‘shit’, which had a very powerful impact on those who heard her. Sonia tried to manipulate the emotions of those in authority by talking and signing about her ‘grief’, although this was eventually met with a very containing response, namely psychotherapeutic intervention.

Entelechy's aim of channelling subversive behaviour into artistic forms such as poetry and drama, which would thus act as a potentially powerful form of protest, clearly did not always happen. Sometimes the agendas of the group leaders took over and they directed the action. Sometimes the people with learning disabilities themselves powerfully subverted the aesthetics which Entelechy was trying to promote, by non-compliance or by 'getting lost in the audience' when giving a public performance. The 'arts', in particular performance, do have the power to transform and can be a radical force for change. However, the heavy structures of day centre life and the norms of mainstream society constantly reassert themselves, constraining aberrant behaviour. Through small acts of attrition, made noticeable during the looser structure of Entelechy's workshops within the day centre, subversive behaviour can accumulate into a new aesthetic, which, if ownership of the action by people with learning disabilities is acknowledged, has the potential to empower them. Entelechy's potential role as a radical transformative agent, impacting on the lives of people with learning disabilities beyond day centre life, needed to be reconciled with its apparent position in maintaining structures of power and its use as a 'safety valve' for non-normal behaviour.

In the following chapter, an 'action research' project organised by Entelechy, and focusing on the life histories of people who have learning disabilities is examined. This project fused a need to record past experiences with a desire to create change in the present social circumstances of those involved. Priority was given to the preservation of 'identity' in a changing service environment. In contrast to most of the informants described in this chapter, many of those involved in the Rediscovering Our Histories

(ROH) project had (often extremely long) experiences of institutionalisation in hospitals, which inevitably impacted on their idea of 'self'. They sometimes recounted subversive strategies from their pasts, as well as survival strategies in the present, as they adjusted to life in *the community*.

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Chapter Seven

Rediscovering Our 'Selves'

i) Introduction

In the histories and advocacy projects we have found that a person's story is so often pathologised and kept in a psychiatrist's filing cabinet. Some people would like to make that into a creative story ... working through the pathology.

Rebecca Swift

The life history is a document of selfhood that emerges from particular kinds of interactive encounters. The self that is elicited is not a timeless, finished product but is rather a fragment of an evolving process. In essence, then, the life history text need not be factual in order to be true.

Angrosino 1989: 105

An important emerging issue over the past few decades has been the question of how people with learning disabilities represent their lives *to* others (which has occurred concurrently with an examination of how their lives are represented *by* others). This question has been paralleled within the human sciences, particularly anthropology. Illness or disability narrative is not a new thing, and there have been several specific attempts to record the life histories of people with learning disabilities (e.g. Edgerton 1967; Langness & Levine 1986; Evans 1983; Angrosino 1989; Atkinson & Williams 1990). The number of publications in this field has expanded in the last twenty years or so, gaining validity as an area of study within the social sciences, and as a therapeutic technique within health and social care. Recently, disabled people have been positively encouraged to write or talk about themselves, and there is an eager market for such literature, with many accounts mixing the political with the phenomenological. In addition, their lives have been brought to public attention through personal narrative based television programmes such as 'The Disabled Century' (shown on BBC2, 1999). To paraphrase Rapport (1998), narrative is the means by which consciousness is pulled

out into the world. In many respects, this interest in narrative is a reflection of a general trend in contemporary Western society. According to Giddens (1991), everyone is engaged in ‘the project of the self in high modernity’:

It is made clear that self-identity, as a coherent phenomenon, presumes a narrative: the narrative of the self is made explicit. Keeping a journal, and working through an autobiography, are central recommendations for sustaining an integrated sense of self.

Giddens 1991:76

As has become apparent in previous chapters, the dominant idea that the Western self is intersubjectively made is thrown into relief in the case of people with learning disabilities. By their very definition as incompetent, people with learning disabilities are seen as in need of assistance to create narrative frameworks for their lives. A project organised by Entelechy to fulfil this need, ‘Rediscovering Our Histories’ (ROH), will be examined in this chapter.

As an example of ‘action research’, Entelechy’s ROH project had tangible effects (mainly positive) on the target population. Ways were sought to facilitate the recording of the subjective experiences of a large sample of people with learning disabilities in south-east London. The purpose behind creating and collating such accounts was to enhance the learning disabled people’s lives in the present context, by helping them to express their needs and desires, and to produce a means through which their ‘identity’ could be both preserved and communicated in a changing service environment. The suggestion by Becker that: ‘Narratives ... arise out of a desire to have life display coherence, integrity, fullness and closure’ (1997:12), was perhaps one reason why a ‘life history’ approach was initially taken by the project, with the aim of re-establishing a coherent ‘normal’ self for the individuals concerned. Many of the people with learning disabilities involved in this project had had their lives disrupted by being

institutionalised and being severed from kinship links, rather than due to a 'biographical disruption' (Bury 1982) following the advent of illness or a recognition of their disability. Indeed, the notion of illness or disability *per se* as 'biographical disruption' has been critiqued from several angles. Of particular relevance here is Williams's (2000) argument that conditions which a person has had since birth (such as learning disabilities) are neither addressed nor easily incorporated within this approach:

Doubtless struggles still occur, whenever the condition emerges. Compared to socially-set standards and cultural prescriptions of 'normality', moreover, the lives of these individuals may appear profoundly disrupted. Yet, phenomenologically and existentially speaking, it remains the case that these biographies have not, in any real significant sense, *shifted*.

S.J. Williams 2000:50 (original emphasis)

If the phrase 'chronic illness' is replaced with 'transformation of the self', perhaps a more useful idea is the reverse notion of '*biographical disruption in the genesis of chronic illness*' (Williams 2000:55 - emphasis in original). The 'self' of the person with learning disabilities is understood to have been transformed firstly through the processes of (often long-term) institutionalisation (what Goffman 1991 has termed as mortification of the self); and secondly by a return to *the community* (a restoration of self). Institutionalisation is not seen here as the 'cause' of a person being classified as having a learning disability (although the iatrogenic nature of institutions has been explored by others; for example, Goffman 1991). Rather, it is the sequestration from, and later re-entry into, *the community* which is seen as having major effects on the selfhood of the person concerned. This was the major issue which the ROH project addressed.

People, whether or not learning disabled¹⁰⁵, do not necessarily create or communicate sequential, coherent stories of their lives. Information about 'the self' and how one presents it is evidently context specific, and changes throughout the life course: 'As people look to the future while simultaneously reflecting upon the past, they continuously reformulate their identities to be compatible with their experience of life. Narrative and metaphor facilitate this integrative process' (Becker 1997:187). As the ROH project developed, the focus shifted from the 'factual' content of the material (textual, visual and oral), to what the persons concerned wanted to express about themselves. This was somewhat difficult to reconcile with the desire within statutory services to produce documents which somehow 'defined' individuals, however informally, which could be used by carers to gain an holistic understanding of the person with learning disabilities.

As this chapter will show, one of the major outcomes of the ROH project was the facilitation of a reunion of former inmates of the old asylums who had been dispersed in the area covered by the scheme. This was the result of the identification of the need to be among one's peers, share experiences, and increase social contacts and leisure activities. This need, which manifested itself to Entelechy facilitators during the project, had been largely overlooked in the planning and execution of 'community care' in the area. As to the question of 'for whom' were such narratives documented, it became apparent from the data that they were written for several audiences, largely at the request of (and facilitated by) care workers and academics. Evidence suggests that such

¹⁰⁵ See for example Vieda Skultans' 1998 'The Testimony of Lives: Narrative and Memory in post-Soviet Latvia'.

narratives may be varied according to the perceived recipient of that narrative. As Davies points out: 'In many cases, individuals will alternate among several imagined audiences depending on topic' (1999:169). Emphasis is often placed on the 'coherence' of a narrative by these audiences, in an attempt to normalise the life stories of the people with learning disabilities with whom they are working. Coherence, however, is 'about belonging' (Skultans 1998:xiii). To understand and 'translate' the narrative of a person with learning disabilities to the best of their own ability was seen as paramount by the non-disabled facilitator. Imposed coherence upon the narrative was therefore seen as a just way of communicating that person's common humanity. However, for many people with learning disabilities, especially those who were classed as having more profound disabilities, coherence was not necessarily meaningful. Therefore, although the project did produce material documentation (in a variety of media), its greatest achievement was perhaps the drawing of attention towards 'narrative as process', or life as it is lived, overturning the hegemony of 'the text' in the creation of meaningful expressions of what it is like to have learning disabilities.

ii) Ethnographic Setting

Between 1996 and 1999 Entelechy organised a major project, 'Rediscovering Our Histories', (ROH), which was co-ordinated by an arts practitioner and academic, Mara de Wit¹⁰⁶. This was funded by the Department of Health (DoH) after a proposal was

¹⁰⁶ De Wit was contracted by Entelechy to design and co-ordinate the ROH project over a three year period. She is a practitioner/researcher engaging in questions arising from education, and the health, care and social sector in relation to aesthetic practice in contemporary society: 'Inspired by the autobiographical work of the artists Freda Kahlo and Maya Deren, 'Self as Source' forms an anchoring line into this dynamic field of inquiry' (Slater & de Wit 'Rediscovering Our Selves' 1999).

submitted by Entelechy which complied with specific criteria, as the DoH had earmarked funds for projects which addressed issues such as social exclusion, older people, 'community presence', history, and the transition from long term hospital care to *the community*¹⁰⁷. Entelechy's project (ROH) focused on the life experiences of a sample of people classified as having learning disabilities, most of whom came from south-east London (largely Lewisham and Southwark), and many of whom had spent large periods of time in 'mental handicap' hospitals (specifically Darent Park Hospital, near London).

The project aimed to assist in the recording of this group's narratives through a variety of techniques and media, including non-textual 'auto'/biographies¹⁰⁸. The sample covered a wide range of abilities, and was a pioneering attempt to include and convey the experiences of people who did not use conventional language. In a continuation of the themes raised earlier in this thesis, namely 'community', 'relatedness', and 'recognition', Entelechy sought to implement such ideas in practice, specifically with

¹⁰⁷ In 1969 59,000 people lived in NHS Mental Handicap hospitals, decreasing to 32,000 in 1986 – source, Booth et al 1990. These statistics, however, need to be compared with the fact that there are more than one million people in Britain who have some form of learning disability, 190,000 of whom have severe learning disabilities – source: Young 1995: 259.

¹⁰⁸ The use of the term 'auto'/biography is meant to indicate the intersubjective way in which these narratives were produced.

this highly excluded sector of the population. Rooted in the aims of the Dartington Conference, 1983¹⁰⁹, the ROH project hoped to generate a sense of ‘relatedness’ in those taking part in this scheme. Such arts practice in *the community* aimed to empower people through encouraging ‘the continuous regeneration of the spirit of community’ (Kershaw 1992: 60).

After some initial preparatory work, the project was launched in September 1996. Mara had distributed a very large ‘mail-out’ about the project to the two main agencies which organised and provided care for people with learning disabilities in the designated area. She met with as many staff training groups and care managers as possible, trying to build a ‘network of allies’ (Mara de Wit). She met with house managers (those who ran residential care units for people with learning disabilities), team managers, social workers, community care teams, voluntary bodies (Mencap, Link), and people involved in befriending schemes. She described this stage of the project as ‘aggressive outreach’. Her advances were met with a mixed response from those organising care. Some people were very hostile¹¹⁰, while others were very enthusiastic, and had already started researching and recording the lives and experiences of the people in their care (usually referred to by them as ‘clients’).

Mara was given a vast amount of material (articles, photographs, stories), largely due, she felt, to the fact that: ‘There was a severe lack of archives of Darent Park Hospital’. The project thus became the repository for many unique pieces of information and

¹⁰⁹ See Chapter Three.

¹¹⁰ Mara felt that this was partly due to the idea that the carers did the ‘hard work’ with people with learning disabilities, and this ‘nice little project’ was coming in, doing the ‘soft’ work. This issue has

artefacts from Darent Park. Such material included first hand accounts of life in a long stay institution, which were sometimes written collaboratively between a 'client' and care worker. The ROH project was intended to be 'action research', in that there were 'no experts'¹¹¹. After the initial impetus of the project, it was hoped that most carers and their clients would carry on the research for themselves. Care staff who had been carrying out this life history work independently, beyond their official job remits, were asked to share relevant information¹¹².

In the Autumn of 1996 a launch event was held for the project¹¹³, which attracted about 120 people. Those attending were a mixture of people with learning disabilities, carers, service representatives, family members, friends, artists and the local Mayor. The more 'able' people with learning disabilities who had heard about the project and wanted to

been raised earlier, and is also touched on again later in this chapter, i.e. the division between emotional and physical labour and the legitimacy of the former (see N.James 1992).

¹¹¹ Except, perhaps, the people with learning disabilities – see for example Knox et al (2000).

¹¹² During the period that the project was operating, Lewisham social services introduced a life-history/narrative approach into its care plans for people with learning disabilities. It was unclear as to whether this was a direct result of Entelechy's involvement.

¹¹³ I was not involved in the project at this stage.

participate came along themselves, whereas ‘less able’ people were often nominated to the project by care workers¹¹⁴, who brought them along to the launch. Many more people applied or were nominated to participate than could actually be accommodated in the initial (pilot) stage of the project. Mara described the launch event as a ‘big theatrical or carnivalesque event’, including exhibitions, visual arts, videos, images and stories; which she felt contrasted very much with what statutory services would normally have provided for this group of people. Attendance at this event was high, perhaps because of the fact that before hand (and at the launch), many of the learning disabled people expressed a strong desire to meet up with old friends and acquaintances from the hospitals after their rather perfunctory dispersal into *the community*. Entelechy emphasised that there was an urgency to collect life stories and document experiences of the ‘survivors’ of ‘mental handicap’ institutions, some of whom were then in their seventies and eighties, as: ‘with them a whole piece of history will disappear’ (Mara de Wit)¹¹⁵.

I suggest that this project was part of a wider aim of Entelechy, namely the recovery of the ‘self’ post-institutionalisation. In some respects, therefore, Entelechy had set itself up as an ‘anti-institution’, seeking to dismantle institutional practice and ideologies, which it felt were still operating (although to a lesser extent) in *the community*. Of necessity, the project was heavily influenced by current social policy rhetoric around

¹¹⁴ It seemed to be the case that individuals about whose history or background little was known were most often selected to participate by carers in the hope of re-forging family or other social links.

¹¹⁵ The idea of collecting narratives before they ‘disappear’ is often cited as a reason for conducting life history research in the social sciences, as noted by Davies (1999: 168). However, as this chapter illustrates, the scope of the project extended beyond this.

‘community care’ and *normalisation*. Ironically, therefore, Entelechy was operating with the backing of the State system which had set up the institutions in the first place¹¹⁶. In recent times rhetoric concerning the care of people with learning disabilities has turned towards ‘recognising’ the ‘individual’. Within statutory services this sometimes took the form of ‘individual needs planning programmes’ (IPPs¹¹⁷). Through the dissemination of the findings of the ROH project in training sessions and by a publication for carers, managers and others involved in service provision for people with learning disabilities, Entelechy hoped to build on and improve these initiatives, giving greater depth to the ‘personhoods’ of the people with whom they worked.

The project co-ordinator, when questioned about the underlying philosophy behind the project, explained that:

It’s about the importance of one’s own history and the connection between memory and self, what one carries from the past into the present and into the future ... that relates to John O’Brien’s principles of normalisation: how people can have viable lives and live in the community - that means more than just moving from residential to smaller housing modelled on family units ... It is about how these people who have previously been segregated really take their place in the community and in society ... having valued roles and earning respect.

I joined the project in September 1997, after it had been running for a year, and stayed with it for approximately 12 months. A pilot study involving 12 individuals with learning disabilities (discussed below) was already in operation. Group and themed activities, social networking and events began to be initiated on a regular basis at

¹¹⁶ See Chapter Two. The 1913 Mental Deficiency Act allowed compulsory segregation of ‘idiots, imbeciles, and the feeble minded’ (see also Thompson 1996).

approximately the time of my arrival on the project. A model was developed and basic procedures related to ROH activity were formulated for training and publication purposes. My role within the ROH project was an active one, as I assisted on the pilot study, attended craft groups and meetings as a participant observer, visited members in their own homes and attended training sessions where findings from the project were disseminated. Being both a volunteer in the project and looking at it objectively as an anthropologist presented some challenges. However, this approach provided me with a role which, I believe, gave me greater access to informants' life worlds, and opportunities for observing them in a more informed way than if I had not been involved in activities. Involvement in this project gave me access to their home environment, outside of the community centres, arts centres and day centres where most of Entelechy's activities took place, enabling me to contextualise their experiences within the wider social network of *the community*. This process of 'contextualisation' was aided by the fact that several of the people with learning disabilities involved in the ROH project were also involved in the Combined Arts projects, thus giving me a more complete and holistic picture of their lives.

Practice developed during the course of the project was disseminated at both local and national levels. This was achieved locally through the development of a training programme devised and implemented for staff teams based in Lewisham in 1998. Other boroughs in London requested support in how to set up life history research with people with learning disabilities. A publication contract was made between Entelechy

¹¹⁷ I attended one such meeting, where the general care of the individual concerned (who was present) was discussed with care professionals and social services representation.

and Pavilion publishers to produce a training pack (containing text and video) to disseminate findings nationally. This pack was co-produced by Entelechy's director, David Slater, and the project co-ordinator, Mara de Wit. The training pack was aimed at a specific audience, namely: 'individuals, teams and services who seek to empower people who have profound and complex needs to become recognised and respected citizens, informing the shape and direction of their own lives and impacting upon the lives of others' (1999:1). Additionally, Open University conferences on Learning Disability were attended annually throughout the project, where contacts were made with others engaged in similar research.

This chapter provides a fairly in-depth account of the ROH project, focusing on specific case studies. I examine the efficacy of the project in bringing about its core aims, which were 'cultural recognition' of people with learning disabilities and the development of sensitive devices for the documentation of their lives, many of whom could not access textual or verbal communication. I also examine the notions of fact and fiction, their relevance for such documentation, and the credibility/usefulness of the various types of 'narrative' produced. Central themes such as 'stigmatisation'; 'mortification' of the self (in institutions), and 'restoration' of the self (in *the community*) are additionally addressed in relation to the data presented. The ultimate aim of using narrative as a vehicle for the production of a culturally embedded self is questioned, as is the notion of 'for whom' such documents are produced.

iii) Disability discourse: Ontological, public and metanarratives

Narrative has both verbal and nonverbal discourse forms ... dance or mime can be narrative, while ritual, whether spoken or unspoken, can memorialize or replicate a sequence of events with the capacity to transform or reaffirm power inherent in a social system ... A narrative may be perceived as incoherent or inconsequential because an outsider does not understand its appropriate significance, or because of the incompetence or insignificance of the report or rendition.

M.Mills 1997: 337

Drawing on the work of Somers (1994), Thomas (1999) has outlined an approach to narrative identity and the disabled self; in her case, focusing on disabled women. This provides a useful framework through which to view the accounts of and by people with learning disabilities in the ROH project, which were collected during my fieldwork.

Thomas argues that:

Self identity is a key element in what I have termed the psycho-emotional consequences of disablism. By these I mean the 'personally or intersubjectively felt' effects of social forces and processes which operate (not in a direct, mechanical or uni-dimensional way) in shaping the subjectivities of people with impairments. They contribute powerfully to the sense that each of us has about 'who I am' (or am prevented from being).

C.Thomas 1999: 48

Rather than approaching narrative purely as discourse, Thomas suggests that Somers' conception of narrative as an 'ontological condition of social life' (Somers 1994: 613-14, quoted in Thomas 1999: 48) is a useful way of looking at disability identity. In particular, Thomas asserts, three of the four¹¹⁸ dimensions of 'narrativity' identified by Somers are applicable to the disabled experience, namely ontological narratives, public narratives and metanarratives. 'Ontological narratives', according to Somers, are 'the stories which social actors use to make sense of - indeed, to act in - their lives. Ontological narratives are used to define who we *are*, this in turn can be a precondition of knowing what to *do*' (Somers 1994:618, quoted in Thomas 1999: 50).

Consequently, Thomas asserts, they come into being through the interaction of inter-subjectivity and public and metanarratives, both temporally and spatially.

'Public narratives' are narratives 'attached to cultural and institutional formations larger than the individual' (ibid.), and when applied to disability cover the 'personal tragedy' of disability; the grotesque/the body beautiful; medical narratives concerning 'abnormality' and 'rehabilitation'; and narratives about 'quality of life', relating to euthanasia and abortion. Finally, Somers suggests that 'metanarratives' refer to 'master narratives', which underscore public narratives, for example 'the Enlightenment' or 'Industrialisation', which form the framework (whether or not this is consciously acknowledged) within which both social actors and social theorists, operate. Metanarratives concerning the disabled, Thomas points out, involve 'the very demarcation of what it means to be "impaired" (the social construction of impairment), to be a "whole" or "less than whole" human being, and thus to be an "acceptable" member of the community' (Thomas 1999:50).

Applying the above to the situation of people with learning disabilities in Britain, the major public narrative which emerges concerns a change in how they are cared for. As discussed in earlier chapters, the location of their care has moved (in most cases) from institutions to *the community*¹¹⁹. There has been a shift in policy towards *normalisation*

¹¹⁸ The fourth, according to Somers, being 'conceptual narratives'.

¹¹⁹ As has already been noted, however, not all people with learning disabilities were institutionalized, but, as I will go on to show, the public narrative of institutionalisation affected nearly all such people, in that it represented what could potentially happen to them.

(a medical/psychological and social policy public narrative)¹²⁰, prescribing that such people should lead 'ordinary lives', the success of which is measured by the 'five service accomplishments'¹²¹: community presence, choice, competence, respect and community participation. The transition from institution to *community* is thought (by social services, care professionals¹²² and Entelechy) to be accompanied by a shift in the 'self' of the person with learning disabilities.

Previously existing in a limited social world of the 'total institution' (Goffman 1991), the newly discharged former inmate was expected to move into *the community*, usually with some kind of professional support, and resituate themselves within kin and social networks. During the many years that the person had been an inmate, they would have undergone what Goffman (1991) has termed the 'mortification' of the self, through various humiliations and debasements, with the aim of making them into pliant subjects controllable by the authorities. The more recent shift in social policy has been towards 'individual' notions of care, as illustrated in a government circular which was concerned with arranging services 'on an increasingly *individual* basis...' (DoH 1992a, para. 9, emphasis in the original, quoted in Collins 1995: 96). On their reintroduction into *the community*, according to the ideology of 'community care', the 'mortified' self is overturned and in its place a coherent, social, reflexive self is to be constructed (a 'normal' self), with or without help from other agencies and individuals (suggesting a highly intersubjective self being created in many cases). This frequently results in

¹²⁰ See Chapter Two.

¹²¹ This refers to the Five Service Accomplishments, outlined by John O'Brien – see Appendix XI.

¹²² See, for example, the volume edited by T. Philpot & L. Ward 1995.

ontological and public narratives being deeply entwined, as some of the case studies below illustrate.

Despite, or perhaps because of, the stated intentions of 'community care', many learning disabled people's lives are still highly regulated and controlled by professionals, and in numerous instances, their lives are not very different from their experiences in the institutions¹²³. True integration with the local non-disabled population is rarely a reality, with the more profoundly impaired being even less likely to interact with their neighbours or *community*.

The general consensus among the British public seems to be that people with learning disabilities should not live in segregated accommodation, but concern is expressed if such people become neighbours. Several of my informants reported attacks by youths and general harassment, after their move into *the community*. Barriers to integration were also set up by the cautious attitude of care staff, who were sometimes suspicious of someone who just 'dropped in' to visit a learning disabled neighbour but who was unknown to the care staff. Learning disabled adults are seen as 'vulnerable', and open to manipulation and exploitation. As a result, many are 'protected' to such an extent that true integration becomes impossible. There is not much evidence either that people with learning disabilities who live in their family home are any less isolated or are more integrated than those who are cared for by social services. Kin networks are often

¹²³ Research by J.Collins & The Joseph Rowntree Foundation supports this claim. See J.Collins 1992, 1993 & 1995.

restricted, and affective ties are difficult to maintain if the individual displays anti-social behaviour, as Hubert (1997) has pointed out.

The most articulate learning disabled people with whom I spoke during my research were frequently concerned about the public's perception of them, wishing to dispel public feeling that they were somehow violent or out of control and presenting a risk. Unlike those people in Edgerton's (1967) study, who were keen to disassociate themselves from ever having been in an institution and the accompanying stigma, most of the articulate people in my study were very forthcoming in talking about their experiences in institutions and how this had affected their lives. This change from the 1960s, I suggest, was largely due to the effect that the disability rights movement has had on this particular group of people¹²⁴. Through organisations such as 'People First'¹²⁵, many learning disabled people have found a voice, and want to talk about injustices which they have suffered. Hence, they are seeking to challenge disablist public and metanarratives through accessing counter-narratives.

Additionally, there is an audience, in the form of interested social researchers, students, some care workers, and occasionally the general public, wanting to hear their stories, which did not previously exist. Like those in Edgerton's study, however, most of the more articulate people in the research sample were keen to pass as 'normal', although the latter group did not deny their institutional pasts. Many of them thus held an ambiguous role as spokespeople for the group defined as having learning disabilities,

¹²⁴ Additionally, the threat of being 'sent back' to institutions has diminished as most have been disbanded, and in the case of Darenth Park, levelled to the ground.

¹²⁵ A self advocacy group run by and for people with learning disabilities.

claiming a shared collective history, while at the same time wishing to distance themselves from this category. Consequently, they were both 'of' this group, and outside it. While the general public and professionals perceived them as having learning disabilities, they, on the whole, saw themselves as competent social actors, who had 'rediscovered their selves'. Ontological and public narratives were, therefore, interwoven into the self-identity of these more 'able' people with learning disabilities, which sometimes resulted in confusion when defining themselves. This confusion was especially evident in those individuals who adhered to some elements of public narratives about disability and some elements of counter-narratives at one and the same time, as illustrated below¹²⁶. My data is largely in agreement with the findings of Zeitlin & Turner (1984) and Angrosino (1989), which indicate that people with learning disabilities are often very aware of the audience to whom they relate their narratives, adopting a variety of strategies, dependent on circumstances. However, their research was predominantly with very 'able' people classed as having learning disabilities. The heterogeneous nature of the category 'learning disability' is often overlooked. This chapter seeks to show that the ROH project applied 'narrative' techniques to a wider range of abilities (including the profoundly disabled), and that creative approaches, beyond the purely textual, were used. The question of whether or not these methods were, in fact, useful to the people with learning disabilities is addressed.

¹²⁶ See also Angrosino (1989), who identifies several 'survival' strategies among ex-institutionalised learning disabled men in Florida, USA, for the presentation of 'self'.

iv) Memory and Identity in the 'Recovered' Lives of People with Learning

Disabilities

People with learning difficulties are not passive. Despite oppression and despite denial of their humanity, people retain an individual dignity and spirit which is hard to destroy.

Brechin and Walmsley 1989:119

A sense of identity is not easily achieved. People with learning difficulties are faced with obstacles at every turn. Their stories witness their battle, often life-long, to overcome these obstacles and find a sense of self ... The battle is both against outside forces (often well-meaning parents and carers) which deny adulthood, and internal learned prohibitions (particularly the internalised barrier to parenthood). The struggle finds expression in the search for, and celebration of, autonomy, freedom and independence.

Atkinson and Williams 1990:217

Entelechy made explicit the process of self-making identified by Giddens (1991), as it highlighted what was 'missing' from the lives of people with learning disabilities, many of whom had previously been institutionalised or sequestered. Entelechy had approached this process of 'rediscovering the self' by focusing on memory and identity. Without memory, it is difficult, if not impossible, for 'the self' (as it is conceived in contemporary Western culture) to exist¹²⁷. It is my contention, therefore, that Entelechy aimed to construct 'memories', irrespective of whether they were fact or fiction, in order to reinforce the idea that all people, however profound their impairment, have a 'self'; and that 'self' contains a coherent narrative account of its life, irrespective of whether or not 'the self' is able to communicate this account to other people.

Two agendas can be discerned; firstly that the aim of projects such as ROH was to access this narrative, using both verbal and non-verbal media, and to communicate it to

¹²⁷ 'My mistake had been to suppose that a memory image could subsist apart from an image of the self, that memories could persist apart from the act of speaking or thinking about them from a given standpoint. It was this junction between past and present that she was losing. She was wondering who the 'I' was in her own sentences. She was wondering whether these memories of a blue beer mug in a warm suburban garden were really her own. Because they no longer seemed to be her own, she began

anyone who may be connected to the narrator's life. Secondly, individual narratives, constructed and recorded by Entelechy, were to form part of a larger project which aimed to act as a testimony to the collective experience of thousands of people with learning disabilities in the twentieth century, and these findings were to be disseminated nationally.

Previously, in the old asylums, records were kept on each of the inmates, who had no control over who had access to information about them¹²⁸. This served, as Goffman notes, to force the inmate into a 'contaminated' relationship with his or her keepers, 'for it is through such perception and knowledge that relations are expressed' (Goffman 1991:35).

With the closure of institutions such as Darent Park, many records were lost or deliberately destroyed¹²⁹. Although sometimes containing derogatory comments, these documents were usually the only record of a person's life, including important details of family members and reasons for admission to the institution. These facts may never be recovered, especially if the inmate's memory or communication skills are in any way impaired. During Entelechy's efforts to retrieve data on participating members who had been institutionalised, they came across many bureaucratic barriers. Hospital

to throw them away.' (Extract from Ignatieff's novel, *Scar Tissue*, exploring the disintegration of the self which occurs with Alzheimer's disease, 1993: 53).

¹²⁸ Records are still kept on people in *the community*, by carers and social workers etc. This is seen as necessary to ensure the well being of the person concerned, and in order to record important information. However, this can still be seen as an oppressive practice as many people with learning disabilities are unable to access these records as they are illiterate, and they have little control over which 'professionals' have access to them.

¹²⁹ Slater & de Wit suggest that old hospital files may sometimes have been discarded due to 'a particular style of recording then employed (now deemed as not useful, often too prescriptive, if not derogatory' (1999: 11).

records which were still in existence were difficult to access, due to new rules about data protection and confidentiality.

The issue of consent to access these records was very pertinent, especially for people who had limited communication skills, and who therefore required someone else to advocate on their behalf. Questions were also raised, such as: ‘Will digging into the past disturb him or her?’ ‘Will members of their family *want* to be contacted?’ ‘Suppose this activity stirs up memories of abuse which the client has learnt to deal with, but does not wish to be reminded of?’. Trying to document the lives of younger people who may not have spent very long in institutions and were now living in *the community*, met similar problems, as current social services rhetoric around confidentiality often placed strict (although sometimes ambiguous) guidelines over what information could be shared with people outside of the care home environment. Within the ROH group great emphasis was placed on ensuring that narratives - even when constructed with a great deal of help from others due to the profoundness of the person’s disability - were focused on the narrator’s needs, wishes and abilities as much as possible. Obviously, this was extremely difficult in the case of people with profound and multiple disabilities, and the influence and involvement of professional care staff had to be constantly monitored to ensure that the document produced did not become a ‘Public Relations’ exercise for their services. Genuine attempts were therefore made by Entelechy to produce something which was ‘authentic’ and true to the ‘individual’, despite being inter-subjectively produced.

Control of knowledge and information continues to be a very important issue in the lives of people with learning disabilities. In modern care homes information is protected, ostensibly for the welfare of their clients, to ensure their privacy and personal integrity. However, I found that this rule of confidentiality was often fairly arbitrarily applied. I was present at several meetings run by social services which were often attended by the disabled person in question, in addition to a large group of 'interested' individuals, some of whom the client had never met. At these meetings intimate details were discussed of aspects of the client's life such as medical problems, their sexuality and financial status. Legitimacy was given to such sharing of information by the fact that the person concerned was present, and consent was therefore assumed, even if that person had severe communication difficulties. Additionally, all individuals present at such meetings were assumed to have the best interests of the person in question at heart, their presence having been ratified by the house manager. Being classed as a 'professional' appeared to allow unlimited access to 'confidential' information, whatever their relationship with the person concerned. The participation of people with learning disabilities in such meetings is often limited, as Whittaker, a social researcher, points out: 'people with learning difficulties are used to a ... passive role, to being on the receiving end of the services which have been planned and shaped by other people who have decided that they know what is best for them' (1997:328). It should be noted, however, that attempts to overcome the difficulties of participation in such meetings by people with learning disabilities have been made by some care workers and researchers. A collaborative approach appears to be the best way forward for people

with limited communication skills, as well as the investment of resources in advocacy and self-advocacy¹³⁰.

As noted above, a biographical or autobiographical approach to the lives of people with learning disabilities has recently gained in popularity both within and outside statutory services, with some carers being encouraged to help their clients record their life experiences. Some narratives have been published; for example, David Barron's autobiography, *A Price to be Born* (1996); and in Atkinson *et al's*, *Forgotten Lives* (1997). This latter volume records the lives of some people with learning disabilities, with an emphasis on oral history. Attempts by others to record the actual lived experience of oppressed people is not a new phenomenon, and has been going on in many disciplines, including anthropology, for many decades. It hardly needs to be pointed out that first hand accounts of the lives of various oppressed peoples, such as women, religious and ethnic minorities, have been in existence for a very long time. Life history and narrative approaches to the lives of people with learning disabilities tread a difficult road between the etic and emic. By definition, people with learning disabilities have difficulty communicating in conventional ways such as writing or even speech. Most 'auto'/biographies are therefore written in collaboration, with a non-disabled person acting as an advocate or an amanuensis¹³¹.

¹³⁰ See, for example: Dowse 2001; Knox, Mok & Paramentor 2000; Whittaker 1995; Sanderson 1995; Brandon 1995.

¹³¹ With the notable exception of Joseph Deacon's autobiography, *Tongue Tied* (1974), 'which was written collaboratively by four residents in an institution. Joseph told his story: one friend acted as interpreter, another friend wrote the interpretation and a third friend typed the written words' (Atkinson and Williams 1990: 6).

Many people with learning disabilities are not able to write, and although a large number of such people may not have the cognitive capacity to be literate or articulate, a fair number of those who have lived in institutions all their lives are quite capable of expressing themselves in this medium. Many were never taught to read or write, however, as it was thought by the authorities to be pointless, and time would be much better spent on manual activities. In spite of this, over the last three decades, during which deinstitutionalisation has increased in influence, many individual narratives of people with learning disabilities have been written. Together these add to existing historical data and objective evidence, collectively making a fragmented history of people with learning disabilities:

In the contest between varying accounts of shared experiences, people reinterpret and discover features of the past that become the context and content for what they will jointly recall and commemorate on future occasions.

Middleton and Edwards 1994:7

Black people were criticised in the nineteenth century for not having a collective history. The slave narrative movement, sponsored by white abolitionists, attempted to show that this was not the case, and published hundreds of individual histories. Equally, people with learning disabilities are assumed by the general public not to have a history. This is partly because they have been a relatively 'invisible' group, due to the fact that many were sequestered in institutions.

Slave narratives and learning disability narratives raise the question of self-creation through representation. Putting life experience into textual form to act as a testimony is utilised in both cases. Ontological narratives, which are mixed with counter-narratives generally asserting a claim for equal treatment or personhood on a par with the rest of

the population, get taken over and incorporated by the political narratives of their more powerful advocates. One difference, however, between the slave narratives and learning disability narratives is that ex-slaves were writing about an 'institution' which still existed, and were campaigning for its abolition. People with learning disabilities who have moved into *the community*, are recalling a life which no longer exists¹³², as the majority of large mental handicap hospitals have been pulled down or deployed for other purposes. Textuality in both kinds of narratives, however, can be seen as of the utmost importance.

As was the case with slave histories, many learning disability narratives collected by sociologists, psychologists and anthropologists were dictated in an oral form. In order to access and document the lived experience of a diverse group of people with learning disabilities, some of whom had very limited communication skills, Entelechy's ROH project created 'lifebooks' for the members through the utilisation of multi-media technology. Photographs and drawings were used to illustrate these accounts and, almost invariably, even the most pictorial document was accompanied by prose. This prose was rarely written by the person with learning disabilities. In some cases, words or phrases which the person had uttered were transformed into coherent sentences by members of Entelechy, forming a narrative. On other occasions, observations of behaviour, such as playing the piano, smoking, or 'facts' recounted by care workers about what the 'member' had been doing in the past week, together with details of his or her history, were put together by Entelechy and made into a written narrative.

¹³² Elsewhere it has been argued that an institutional mentality still exists within some areas of 'community care', but the material form and way of life of the old asylum has all but disappeared.

Slave narratives were written for a clearly defined audience, their aim being to add weight to the abolitionists' cause and to provide factual documentary evidence to (white) people not yet converted to the cause. This was why, according to Olney, the vast majority followed a similar format: 'the slave narrative, with very few exceptions, tends to exhibit a highly conventional, rigidly fixed form that bears much the same relationship to autobiography in a full sense as painting by numbers bears to painting as a creative act' (1985:150). The reason for this was to give an account of slavery 'as it is', containing no fiction, or acts of '*poiesis*' (ibid.). The narratives therefore, take on what Ricoeur has called an 'episodic' dimension, involving the purely chronological documentation of events. This is contrasted to the 'configurational' dimension of a narrative, which 'construes significant wholes out of scattered events'¹³³, and involves the use of memory, 'shaping the past according to the configuration of the present' (Olney 1985:150).

Learning disability narratives which have been recounted by people able to speak, often take on the form of a similar episodic testimonial as the slave narratives. For example, they usually start, as do most slave narratives, with 'I was born ...' They differ, though, in that the majority of slaves were not told the date of their birth, and had their identities even more debased than people who had spent years in institutions. In fact, certain aspects of the lives of people with learning disabilities, such as pathology, behavioural problems, and family background, were often meticulously documented in the asylum records. Many of the learning disability narratives then go on to document

the year, place and circumstances of their institutionalisation, followed by a detailed description of their lives in the asylum, and the indignities to which they were subjected.

In the rest of this chapter, I examine the various forms that the learning disability narratives and ‘auto’/biographies took, within the ROH project. These fell roughly into the following genres:

- *oral*, transcribed by a non-disabled amanuensis;
- *self-written*;
- *pictorial* (drawings usually done by the person) with text added by a non-disabled person, and sometimes dictated by people with learning disabilities;
- *photographic* narratives, accompanied by text written by a non-disabled person, usually compiled from records, and by interviewing relatives and carers, (most often used for people who could not communicate verbally);
- *video and computer graphics*, also usually compiled by Entelechy for a person who couldn’t communicate verbally.
- *textual narratives compiled entirely by carers*, drawing on a variety of sources, including interviews with relatives and former carers, archive data such as hospital records, birth and death registers etc¹³⁴.

These narratives/‘auto’/biographies fell approximately into two categories: those dictated or written by people who could talk, and those constructed by others for people who couldn’t communicate easily either verbally or in any culturally recognised

¹³³ Ricouer (unpublished), quoted in Olney (1985: 150).

way. I begin with the first category, which presents data that is fairly unproblematic to analyse as it is composed of first hand accounts. Narratives created for people who cannot communicate verbally, taking both textual and visual forms, obviously present more complex issues of interpretation.

v) First hand accounts

For many people involved with the project, the old mental handicap institution on the outskirts of south-east London, Darenth Park, was something of a cultural icon. Many people spent more than sixty years in the institution, which had therefore been the dominant influence in their lives, and remained a frame of reference through which to interpret all subsequent experience. The narrative of Harry Black¹³⁵, who documented his experiences in Darenth Park (unpublished), raises some interesting issues. He entered the institution as a young boy and spent most of his life there. His experiences, and those of other members of the project who had been in this institution, bear testimony to the existence of the processes described in Goffman's *Asylums*. On arrival at the hospital the new inmate was subjected to various rituals which served to mortify the self, and vestiges of their previous identity, such as their own clothing and personal possessions, were usually taken away:

I was taken into a side room and was told to strip off and get into bed. Then the Doctor came and thoroughly examined me and told the charge nurse to keep me in bed for a couple of days ... I was in bed for three days. I just had to lie there. My mother gave me some books and comics to bring with me when I left home, but they were taken away with my clothing. At last my three days had passed by and a nurse brought me in a bundle of clothing and told me to get dressed. I opened the bundle and I think I cried when I saw what I had to wear. The shirt was all sewn in different places; the vest was

¹³⁴ In some cases releases in the local press were used to try and contact people who knew the person concerned.

¹³⁵ This document was given to the ROH project during the initial stages, and was dictated by Harry Black (a pseudonym) to an ex-care worker just before Darenth Park's closure.

flannel and very thick and small and I had a pair of knickers with a patch of different material each side of my behind. When I put them on they were very tight.

Harry Black (unpublished)

Evidence suggests that upon entry into asylums new inmates were often treated roughly and subjected to punishments and humiliations, apparently in order to ensure their future compliance. For example, David Barron¹³⁶ (who was in Whixley Hospital in Yorkshire) was placed on the punishment ward when he first arrived at the institution:

The ward seemed like a prison ... I was shown my bedroom and given a night-shirt to wear. The attendant locked me into the bedroom. I crawled into bed and cried my eyes out. I learned later, I was in the punishment ward. It was an institutional ruling that you spent the first few months there.

Barron 1989:121

The inmate's body was further disciplined through control of bodily practices such as shaving, using the toilet, washing, smoking, being spatially confined: for example, to the ward, to bed rest or locked in a seclusion room in solitary confinement. Any family members possessed by the new inmate were discouraged from visiting, serving to sever further the link between the inmate and the outside world. In the course of my fieldwork, I came across very few people who could recall what their life was like prior to institutionalisation. In the Crafting Our Memories¹³⁷ group, when pressed to recall their childhood or family home, most people created fictive accounts and pictures of dwellings and incidents which had never occurred, often creating idealised representations of what they perceived to be a 'normal' childhood and home. For many in the group, the only reference point they had of living in a house, was the place where they were living currently, and consequently several of the group chose to depict this.

¹³⁶ I met David Barron at an Open University conference in 1998, attended by members of Entelechy, where he was one of the speakers. Using his real name, therefore, seems appropriate as he has published an account of his experiences.

¹³⁷ A craft group for older people with learning disabilities, set up as part of the Rediscovering Our Histories project, which is discussed later.

Institutionalisation, as Goffman has accurately described, strips the new inmate of his or her previous identity and self, to be replaced, through a 'series of abasements, degradations, humiliations, and profanations' (Goffman 1991: 24) by a mortified self, with changing perceptions of his or her relationship to themselves and others, during their 'moral career' (ibid.). Following on from rituals of mortification on first entry to the institution, Goffman asserts that 'the self' is further corroded by the disruption of 'role scheduling', by which an inmate's previous separation of roles in civilian life is replaced by 'role dispossession', where roles are merged into one and the inmate is no longer able to maintain a multifaceted self. The new inmate is objectified, absorbed into the institutional machinery, with detailed records being made of physical features, including any pathology, and all aberrant behaviour is recorded. Standard clothes were issued and inmates were expected to behave in a uniform way with the rest of their peers; for example, bathing at the same time, going to bed and waking at the same time, with personal effects and idiosyncratic behaviour heavily controlled. As was also the case with American slaves, their adult status was corrupted - they were often referred to as 'boy' or 'girl' whatever their age - and treated accordingly as having diminished rights, or in some cases no rights at all. As Goffman suggests, the physical integrity of inmates could not be guaranteed. Inmates of mental handicap institutions were often subjected to beatings, forced labour, restriction of food and general abuse, as a further extract from Harry Black's narrative illustrates:

The next morning the nurse told me I would be going to a ward to live with boys of my own age ... the nurse came from the office with some papers and told me to go with him. He took me down a very long passage which was called the 'corridor'. He started to walk quick and I tried to keep up with him and fell over. He pulled me up by the

back of my collar and smacked me around the ear, then he dragged me along the rest of the way.

Harry Black (unpublished)

Harry Black, as well as being classified as having learning disabilities was also physically impaired, with limited movement in his legs. When he was institutionalised, walking aids were taken away from him and he was forced to try to walk without them. Attempts were made to 'normalise' his 'deviant' body through coercion and the threat of punishment. Over time, Black incorporated the institutional ideology within his idea of self, and began disciplining his own body. He thus incorporated within his ontological narrative, the public (medical) narrative of 'abnormality' which is that it should be overcome by 'rehabilitation':

When I was able to get on my legs a bit I used to hold onto the wall for support and some times I left dirty hand marks on the wall ... I was told not to hold on ... the next time that nurse caught me he gave me a bang on the head. After that I tried very hard to walk without holding on, I had many bad falls and hurt myself many times but I was beginning to improve. I could tell I was getting better and better so I did not care how many times I hurt myself, I was not going to give in. It took me about six months to get myself to have a steady walk ... and for once I got a friendly pat on the back from the nurse who had made me walk without support. I soon was able to walk as good as anyone, which made me more contented than I had ever been before.

Harry Black (unpublished).

At the end of giving a detailed account of his life in the institution, and of the changes he saw happen, Black interestingly concluded his written account with an apology for the style of his narrative, saying that he was 'not a very good story writer but I have had a good try', in a similar way to how many slave narratives incorporated such an apology, bringing further testimony to the fact that their account was a genuine one, and had not been creatively embellished.

Several other oral 'narrative' recollections of institutional life were given by people with learning disabilities at the 'Review Advisory Panels'¹³⁸. The Review Advisory Panel (RAP) was a meeting held at three monthly intervals throughout the ROH project, composed of a core of people appointed by Entelechy and invited guests, including people with learning disabilities, who commented on and informed the practice of the project. Nancy Johnston¹³⁹, a woman with learning disabilities (mentioned below), who attended a RAP, gave evidence which showed how inmates' sexuality was tightly controlled. She described how once a week the inmates would gather in the dance hall, with men on one side, women on the other, and the staff in the middle: 'The men got up and asked some of the ladies to dance. They danced all the way around the staff; but as soon as the music was finished the men had to go back to one side and the women back to the other, because you couldn't mix' (Nancy).

Homosexual encounters appear to have been fairly common, and were less threatening to the institution than heterosexual ones, as they would not result in the reproduction of more 'defectives'¹⁴⁰. Sam, a man in his eighties who attended a RAP, alluded to the fact that he was an attractive young boy, in whom some of the other male inmates were interested sexually, although he did not go into details. Sam had spent over sixty years in Darenth Park. He spoke about many of his experiences there, including the weekly ritual of bathing:

You were called down the corridor once a week to have a bath ... They had one hundred and twenty patients to wash. Mr. Benson used to let some boys go down the

¹³⁸ Which were tape recorded and transcribed by myself, with the permission of those speaking. The transcripts were utilized by both myself and the ROH project.

¹³⁹ A pseudonym

¹⁴⁰ See Wright & Digby (eds.) 1996 for a comprehensive review of learning disability throughout history, including references to how their sexuality was perceived and controlled.

corridor Fridays, the day before, 'cos we used to help him out ... get a bath before everyone else! ... Mr. West who was in charge used to make six boys get in one water - just a drop of hot water. He told me to get in this water once, but I said never in my life. He said "You're fussy". I said "I'm not bathing in someone else's water". He told the boys to fill it up, otherwise Sam won't get in ... do you blame me? We had to queue up to get a bath and we all had to stand in line with no clothes on ... with all the staff looking at us. I used to say to the staff, "There's a nice picture". I wasn't shy.

Currently, Sam lived in a house in south-east London with John, a man in his seventies, who also came to the meeting, and Danny (later realised to be an important character).

These men became friends when in Darenth Park; all three of whom had spent most of their lives there. This was one of the few successful placements which I encountered where people had actually chosen to live together¹⁴¹. The men were quite competent, and did not have live-in care workers, but were visited daily by support staff. I visited the men at their home several months after the RAP meeting, and observed that they still lived their lives according to institutional routines, getting up early in the morning and going to bed early, and having their meals at set times. During a RAP meeting, Sam told the group about Danny's ledgers (described below), and seemed very proud of them, saying that he 'writes everything down'. Sam had a very strong personality, and frequently got into trouble when he was in Darenth, spending much of his time on the 'punishment ward, ward 9'. He was very forthcoming in relating his misadventures, often small acts of attrition against the institution. These misadventures were what Goffman would term 'secondary adjustments', which 'provide the inmate with important evidence that he is still his own man, with some control over his environment' (Goffman 1991:31).

¹⁴¹ In the course of moving into *the community*, many life-long relationships between inmates were broken up. Many of these relationships were not acknowledged by the authorities who were orchestrating the change, often due to the fact that many people were not considered to have the capacity to form meaningful relationships, especially if they were non-verbal. Evidence uncovered in

During the RAP, Sam and John related many stories from their lives in Darenth Park. An interesting dynamic occurred, whereby John would refer to an incident, and Sam would take over and tell it, as he was the more articulate one. However, before they began sharing their stories with the rest of the group (which consisted of the project coordinator, myself, Caroline who was a local authority's Service Broker¹⁴², and Graham, who worked for a mental health charity), Sam and John checked out whether they could trust the group, asking them whether they used to work at Darenth as staff. Sam started calling Graham 'sir', using the institutional frame of reference under which he had spent most of his life. Graham asked him not to call him 'sir', and replied that no one in the group had worked at Darenth, but some of the group had been instrumental in its closure. Sam and John seemed satisfied with the response, especially when it was explained that the group were interested in their lives and points of view for the purpose of documenting their experiences to improve other people's understanding of their past, rather than for any ulterior motive. Sam and John¹⁴³ seemed to enjoy talking about their lives. A few examples of their stories are given below as a means of illustration:

Graham: Do you remember the war then?

Sam: West Norwood, 1914 ... I think I was 4 or 5 when the war started. The first war. The second one, 1938 wasn't it? Six years war. Consequence I had a breakdown - first war or second ... doctors ordered me a tonic - took it at eight o'clock every night ... I couldn't get no sleep. The boys asked me if I heard the noise, but I was flat out asleep.

Graham: The place got bombed, didn't it?

Sam: I'll tell you what ... one morning, eight o'clock ... boys asleep in ward ten with me. Number eleven ... two wards together, went over ... The Doodle Bug stopped, shook all the wards around the hospital and all the windows had to be boarded up with plywood. Old Hitler said ... that Sam Spencer - I'll bomb him out!

the course of Entelechy's work, however, shows clearly that almost all the people engaged in the project were able to recognize, and feel the absence of, 'significant others'.

¹⁴² A 'Service Broker' in current social services/health care parlance is someone who negotiates 'packages of care' for people with learning disabilities.

¹⁴³ Pseudonyms are used throughout their accounts.

Graham: It had your name on it?

Sam: I told the staff - a rubber aeroplane, don't be daft - don't talk rubbish. A rubber aeroplane! Stops doesn't it? Has no men in it. Some folks were saying that there was men in it...

John: Listen, Listen ... Mr.Barfield ... he's a bishop now!

Sam: I'll tell ya'. He was a clergyman, a vicar, he was at Darenth.

Mara: And he became a bishop?

Sam: They had a little stage, but they knocked it down ... I think I was a schoolboy - 1924 ... school hall, they found him under the school hall, knocked out, unconscious, Danny told me... you know Danny Ryan?

Mara: Yes.

Sam: He's got all these ledgers where he writes everything down ... Next time come over and have a look, he writes everything down.

John: Listen, listen, tea urn ... slippers.

Sam: Wait a minute John ... I was working on the bottom floor ... when I came down I saw three staff in the office having cups of tea. What made me go down ... what made me go under the staircase ... consequence I saw a pair of slippers ... you know, leather-dyed. Well I put them in the tea urn. Well the porter came up - 'two tea urns please'. Two boys took them up and put them on a trolley ... they took it down to the kitchen, filled it up with tea. Whoever filled it up couldn't see right down the bottom ... never been cleaned out hardly. The slippers dyed the tea blue! Mr.Benson, second in charge in ward ten, said 'start filling the jugs up', by then I'd run upstairs ... the boys on my table asked 'Do you think Sam done it?', but Mr.Benson said 'No, he's my right hand man!'

The intersubjective nature of their accounts was particularly noticeable, as was their obvious enjoyment in their performance. In addition, Burke's terminology of the 'biographeme' can be applied to Sam and John's recounted incidents. Burke suggests that 'As the morpheme is to the linguistic analysis, the mytheme to myth, so the biographeme is the minimal unit of biographical discourse' (1998:38), and that 'the biographeme is all that endures once a life has run its course: those moments that can be stilled, pictured.' (1998:39). The non-sequential character of some of the oral narratives, makes them stand out from the textual ones. As soon as they were written down, however, the temptation was, for both Entelechy and care staff involved, to contextualise them biographically, placing them within an episodic narrative. This had

the consequence of making the narratives less authentic representations of people's experiences as they were actually remembered by them. As will become clear when I look at the non-verbal and non-textual 'narratives'/'auto'/biographies later, these narrative forms are less constrained by the need to be sequential, and greater reign is given to the creative imagination in the construction of memory and identity than the oral and textual narratives just mentioned¹⁴⁴.

The importance of reading and writing to one's identity was recognised in the case of one of Entelechy's ex-institutionalised members, Danny. Much excitement was engendered in Entelechy's ROH team upon the discovery of Danny's ledgers, which at first were supposed to consist of several volumes of hand-written prose about his life in Darenth Park. The fact that Danny was able to articulate his experiences in textual form was seen as a great achievement and proof that he had insight and humanity. However, on closer inspection, it was obvious that some of his ledgers relating to the closure of Darenth Park consisted of newspaper and magazine articles about this closure, which he had copied by hand into his ledger. Rule books and other memorabilia from the institution, including original documents detailing the minutiae of institutional life such as visits, correspondence and incidents, also formed part of his ledgers. These provided primary sources from which his personal experience could be verified. Not all the material was an original narrative, written in the first person. However, it was collected together by someone with first hand experience of his subject. I suggest that the fact that Danny was able to select relevant data and compile a dossier on institutional life,

¹⁴⁴ Issues of 'fact' and 'fiction' will be addressed later. It is important to point out that the oral and textual narrative described were often a mixture of both.

despite the fact that some of the text was not original, challenges his status as 'learning disabled'. He was therefore, something of an anomaly. Danny appeared to have been a central figure for many of the inmates at Darenth Park. As someone who could read and write he acted as a fount of information for them. In this case, Danny's ability to translate his experience into text obviated the need for Entelechy to act as interpreters of his narrative. After his move into *the community*, he continued to document his life and the lives of those around him, as mentioned above by his housemates Sam and John. Danny was thus providing a testimonial to their lives. Danny died in the summer of 1999.

As mentioned previously, many people who went into the institutions were deliberately dis-embedded from kin-networks on the 'outside', and thus had their identities further debased. Sam's family had tried to get him out of Darenth Park when he was still a young man, but this was not allowed: 'My mother said "can I take him?" and they said they were sorry ... they thought there was something wrong with me ... they should know' (Sam). Families therefore had limited influence over what happened to their relatives, especially if they were poor and working class. Many of the people I came across who were involved in the ROH project had lost contact with their families as a consequence of institutionalisation. This also applied to much younger people who were in their thirties, and who had spent some time as inmates in asylums. Attempts were made through the project, to re-establish kinship links, which met with a very mixed response. I discuss this later in the context of the 'individual pilots'.

One of the few women whom I came across in the study who spoke in a 'coherent' (culturally normative) way about her life, was Nancy Johnston. She was very used to speaking about her life at meetings, and an academic had previously recorded and published her dictated narrative. Nancy knew very little about her own background, apart from the fact that in the 1940s, at four weeks old, she was placed into care and her mother was detained in Darenth Park Hospital after she was found begging on the streets. She had tried to find out more about her mother, but had had little success. Nancy was transferred to another 'mental handicap' asylum on the outskirts of London, when she was twelve. She came along to some of the histories project events, including a RAP meeting, where she talked about her experiences. Nancy was vehemently against institutions and thoroughly enjoyed her new life in *the community*. She belonged to the self advocacy and disability rights group, People First, which had empowered her to speak out against what she saw as being wrong with the treatment of people with learning disabilities. An example of her thoughts on this subject is as follows:

I think everybody ... you all have your own rights, don't you? So I think that just because somebody can't speak or whatever, they should still have the same rights as everybody else, even if they don't talk. There's always a way of trying to make someone understand. I always say, in the conferences I've done, if somebody can't talk, you say to them OK ... I'll give an example ... she wants to go to the ladies ... you ask her, and you say 'do you want to go to the ladies?' OK, if you can't speak, tell by your eyes. Wink once if you don't want to go, if you do want to go wink twice, and that tells you ... or the other way is nod your head if you do, like that, or if you don't, do that ... The people who can't talk or the people who are deaf, or the people like my little friend at the day centre, those sort of people are very difficult to get to, but there is a way. There is a book you can get that's got the thimbles¹⁴⁵ (sic.) in it and you show them the thimbles, or you ask them to wink their eye or nod their head.

Nancy's view was that everyone, regardless of cognitive ability, was capable of communicating through some shared cultural sign system. They are thus human, and

deserving of being treated with respect. Her ontological narrative had been shaped by a strong counter-narrative, obtained through participation in the disability rights movement. She had appeared on television talking about her life, and was very proud of the public recognition that she gained, and of consequently being invited to conferences and meetings. Like Harry Black, Sam and John, Nancy was aware of, and objected to, the indignities and attacks on the self that she was subjected to in the institution. She found particularly offensive the names and labels which the inmates were given such as 'idiots' and 'mental defectives'. As in Darenth Park, inmates in the last institution where she had lived did not have their own clothes:

They used to have a big cupboard in the wards and you just helped yourself. If you had one dress on one day, the next day somebody else would have it on because it had gone to the laundry and come back again ... I find now it's lovely because I can just wear my own clothes, and nobody else is going to wear them.

Extract from RAP meeting with Nancy Johnston

Nancy moved into *the community* when she was in her early thirties, having spent her entire life in 'mental handicap' hospitals. She said that she found adjusting to living in *the community* quite hard and frightening at first:

We had to learn to get on a bus, learn to get on the train, and if you can't read it's much more difficult. It took a long time to get on and do these things, because you'd never seen money in the hospital. You didn't know what money was like, so when you came out of the hospital it was very hard for me to get used to money as money is. But now I'm OK, I do go out and buy things for myself. In the hospital you didn't get a choice but in the community you get a choice of all different things, a choice for what you eat, and a choice for what you can wear, and it's great. I like it, because I have that choice.

Nancy Johnston

Nancy told the RAP how she felt about talking about her life in public at conferences and on television. She said that it sometimes helped her come to terms with what had

¹⁴⁵ I presumed that she was referring to 'symbols'.

happened in her life, and that she wanted the public to understand that people with learning disabilities:

Do not hurt other people ... they've had a hard life ... they've been shut away and not seen ... I think it's great, it just tells the public what its all about and why ... people with learning difficulties won't murder anybody, or rape them ... it makes me pleased that I can explain these things to people.

This last statement seems to imply that Nancy saw herself as a cultural ambassador for people labelled as learning disabled, although there was a certain hint in what she was saying that she saw herself as 'apart' from this group, that perhaps she was wrongly diagnosed. However, she felt she could speak as both an insider and an outsider. Nancy expressed that she did not get upset when she recalled her life in institutions, remarking:

What for? It's not going to bring my life ... my childhood back again, is it? And it won't bring any of the other's back, will it? In them days, the public were frightened of people with learning difficulties. In them days it was the public's fault what happened to me and a lot more people, because they were frightened. They didn't understand.

Nancy felt that she had changed the perceptions of many members of the public when she talked at conferences and meetings. She was on something of a crusade, visiting day centres, talking to staff, getting people to understand what life had been like for her and many others who had been institutionalised, and explaining how they wanted to be treated now.

Through the project, I met two older women with mild learning disabilities who had spent little or no time in institutions but who had had their ontological narratives strongly shaped by the public narrative of the time, which was that such people should be institutionalised. Olive, who attended several of Entelechy's groups and had been involved with them for many years, said that she felt lucky that she had never been in an

institution. Sheila, who attended the Crafting Our Memories Group, exaggerated the amount of time she had spent in an asylum, and used other people's accounts of institutional life to make up her own autobiography, which was a mixture of 'fact' and 'fiction'. Olive, like Nancy Johnston, was very keen to assert that she was different to the rest of people classed as having learning disabilities. She referred to this group as 'them', and seemed confused over whether or not she felt that 'they' were a threat to the rest of society:

Say, for arguments sake, they were put away for being violent, and they don't remember what they've done, well they'd have to go back on the records, wouldn't they? ... If they have done something violent they are a danger, aren't they? ... They should see if there is anything on the records that shows they're not quite right ... they might not have meant it at the time ... But it's got to be recorded, know what I mean? In case they do it again ... not that I want anybody to get, what do you call it, but you never know, do you? ... 'Cos if they've had an unhappy past, its going to make them violent. People making fun of them ... they're going to retaliate ... they shouldn't be labelled as violent.

Olive

Olive was clearly confused as to what she actually felt. The public narrative of 'the mentally disabled as a threat to normal society' plagued her, and she wished to distance herself from this category of people, although at the same time she partially acknowledged that she was part of this group. There is a clear divide, therefore, between people with learning disabilities who are capable of advocating for themselves, and those who have to rely on others. The fact that they are all classed within the same category leads to an assumed homogenisation of their experiences, which is clearly not the case.

The 'more able' people with learning disabilities are often thought to be more capable of communicating with the 'less able' than a so called 'normal' person. This may well

be the case, as many of them have shared wards, dormitories and day centres, and got to know each other intimately. However, this was the result of enforced proximity, not a 'special gift', due to a shared perceived cultural incompetency. Several of the women whom I came across in the project had worked in the institutions caring for those more severely disabled than themselves, and one continued to do so, but now in the capacity of a 'volunteer'. There is evidence, therefore, that the more able people with learning disabilities were used as intermediaries between the staff and the most profoundly disabled (often as a source of unpaid labour). One could say there appeared to be a scale of incremental humanity, with the 'low grades' and their often uninhibited bodily behaviour being dealt with, in the past, mainly by the more able people with learning disabilities, thus creating a buffer between the inmates and the staff.

All of the people mentioned so far were articulate and able to compose narratives of their lives, either orally, or by writing them down for themselves. However, within the following accounts, which cover a wide range of people with very differing abilities, are those which try to relate the experiences of so called 'low grade' people, most of whom have difficulty communicating verbally, or through sign language, and therefore are assumed not to have access to a cultural reservoir of shared ways of communicating.

vi) The Pilot Study

Many adults with learning disabilities, including people who have profound disabilities, are able to remember both past and immediate experiences. The central concern is the individual's ability to communicate and recall the experience to others. People who are unable to use conventional forms of communication, such as talking, inevitably lack opportunities to build on the experience of the past when forming choices about what to do in the present. In addition, there are fewer opportunities for reciprocal exchanges between the individual and those who support her/him.

Slater and de Wit 1999:2

As already stated, during the period from September 1996 to September 1997, Entelechy had carried out fieldwork in the London Boroughs of Lewisham and Southwark which established contact with local service providers and *community* homes for people with learning disabilities. A pilot group of people were selected, who were to be assisted in compiling their own life history/'auto'/biography, and individual 'tracing' activities were begun formally in January 1997. The people involved in the pilot fell roughly into two groups. The first group included people with little means of verbal expression and high support needs. These were often not older than 40 years of age, and were put forward by members of care staff. The second group included older people who had spent many decades in asylums (predominantly Darenth Park), and who now wanted to 'make a connection with their remembered family, roots and background'¹⁴⁶. Mara noted that requests for participation in the individual pilot were higher than she had anticipated:

Twelve people were selected for the pilot group, covering a range of people in terms of ability, age, gender and cultural background. Most of the individual pilots undertaken... involved staff team members, service house managers, as well as key care workers ...The tracing and establishment of contact with long lost family took place with different outcomes; some positive, others requiring support of a bereavement and counselling nature¹⁴⁷.

I joined the project at a point when the pilots were coming to a gradual end (September 1997). This gave me the opportunity to review the project so far, and be involved with individual cases as they were coming to a close. I attended several meetings with various pilot members in their homes, and was able to observe the outcomes of their involvement with the project. One of the original aims of the project was to relocate lost family members and friends, after the years of separation many had experienced

¹⁴⁶ Taken from the Progress Report 1996-1997 to the Department of Health, by Mara de Wit.

whilst living in institutions. Being embedded in a network of kin was therefore seen by Entelechy and, I suggest, the wider British society, as a major factor in a person's identity. This apparent necessity for the existence of interpersonal relationships to produce a coherent self (post-institutionalisation¹⁴⁸) in people with learning disabilities, draws attention to this process in wider society: 'whilst members of contemporary "Western" societies often conceive of themselves as unique autonomous entities, such a notion of person and self is often dependent upon, and realised through, interpersonal relationships which are themselves based upon a certain level of mutual autonomy' (Lawton 2000:5)¹⁴⁹.

However, as Entelechy acknowledged, when tracing the history of a person with learning disabilities, the 'concept of "family" may have to shift towards "significant others", including staff and fellow home sharers' (Slater & de Wit 1999:14). Below I have outlined two case studies from the pilot group, both of which concern individuals who had limited communication skills, and who were considered to have quite profound learning disabilities. Attempts were made by Entelechy and care workers to find out as much as possible about their backgrounds and compile 'auto'/biographies or 'life books', consisting of text, signs and photographs, which could be used by the person concerned to convey a sense of themselves to others such as new care workers, and to try to retain 'facts' that tended to get lost over time. In recent years some service providers have taken on the idea of collaboratively producing 'life books' with people

¹⁴⁷ Also from Progress Report 1996-1997.

¹⁴⁸ In institutions 'the self' is officially defined as part of a collectivity, i.e. one is an 'inmate' first, as opposed to a 'person'. Obviously attempts to resist this process may produce a more independently defined self/personhood.

in their care, which contain life history information, items about activities and interests, and which list significant people in the person's life. They try to be 'person centred' in that they are usually written in the first person with as much input as possible from the individual whom the book is about. From the pilots, Mara developed a transferable model for tracing histories and making life books and other documents which were potentially accessible to both carer and 'client'. One way to increase the accessibility of such documents was thought to be through the use of photographs and other visual and tactile multimedia, and this was explored by Entelechy.

The following case studies are not presented in the form of narratives, but rather aim to give a thumbnail sketch of the lives of two people with profound and multiple disabilities who were involved in the pilot.

Case study 1: Philip

Philip had profound learning disabilities and also physical disabilities. Various ways of making a 'lifebook' which could be accessible to him were explored; for example through the use of various textured materials and the building of photographic collages and 3-D objects. However, as the following notes show, the most beneficial aspect of the compilation of his history was the changes which were the direct result of taking part in that activity. After this involvement Philip was increasingly recognised as more of an 'individual' by his carers. Some of the observations made are drawn from when I visited Philip in his home in December 1997. Other information was gained from

¹⁴⁹ See also Strathern 1992b; Giddens 1991, 1993; Berger & Luckmann 1971; Luckmann 1967; Lasch 1977; Zaretsky 1976; and Rose 1990.

conversations with Mara, and notes and materials (such as photographs) already compiled with a view to making his lifebook.

Philip was aged 38, and lived in a flat with one other learning disabled man with 24 hour support staff. He was non-verbal and had multiple disabilities. He did not use sign language. When Mara first met Philip, his room had been cluttered and impersonal. When she went to visit him, she took him for a walk in the garden of the group home, which the care staff thought was a very odd thing to do as he mainly used his wheelchair and didn't go out much. Old photographs had shown Philip standing up, and Mara was intrigued as to why this no longer appeared to be happening. There were many staff changes in Philip's home, so it had been difficult to build up any sense of consistency, and his potential ability to walk outside the house had been overlooked. He seemed to really enjoy his outing with Mara, and was later taken for lots of walks by care staff. His life was really transformed through his involvement with the pilot study: 'He was seen as just a body ... now he is seen as a person' (Mara). This was attested to by the service broker, who rang Entelechy to say what a positive change had occurred in Philip's life since his involvement in ROH.

Sensory stimulation was very important to Philip; 'Words don't have much meaning for him' (Mara). After the initial input by Entelechy, he was given an aquarium for his room; he started to have regular aromatherapy sessions, and he enjoyed listening to tapes of Gregorian chant. Mara felt that ROH's involvement had had a snowball effect, with staff in the home initiating changes after the initial impetus. Entelechy's involvement with Philip had produced different results to those that had been expected. ROH had aimed to re-establish family contacts, but instead Philip's 'quality of life' has been much improved. These consequences, it was suggested, were possibly better for him, both in the immediate sense and in the future, than the expected aims. In addition, his level of interpersonal relationships increased. He had greater contact with staff, and was embedded in what could be termed a 'pseudo-kinship' network. Together these worked to bolster his 'self'.

Entelechy had initiated the making of a 'Yah' box for Philip. This was a box covered with photos of Philip at different ages into which it was hoped objects from holidays or things that he liked would be placed, making a sensory record of his experience. A prototype tactile book¹⁵⁰ was made for him by a member of Entelechy, with bubble wrap and cardboard for pages.

¹⁵⁰ The tactile book was for use by the owner who was sensory and mentally impaired, replacing text with tactile media.

In this case study, it can be seen that what was regarded by Entelechy and others as a positive change in Philip's life occurred after involvement with the project. He was no longer seen as a 'docile body'. Familial relationships were not re-established, but due to the strengthening of interpersonal relationships with staff he was seen as more of an 'individual', despite the persistence of his extreme dependency.

Case Study 2: Edward

Edward was already well known to me through Ambient Jam. At a meeting taped by Mara and transcribed by me, his carer, Sharon, described in detail (with Edward present) how she had tried to trace his history and compile a lifebook for him, with much of this activity taking place before the involvement of ROH. Sharon's efforts had led to Edward being one of the few people in the pilot for whom kin relations were re-established.

Edward was a 35 year old man who had profound and multiple disabilities. He had cerebral palsy and walking difficulties associated with an accident which had occurred several years ago. He was described as an 'elective mute', choosing not to speak, although he was able to. He lived in supported accommodation with one other disabled tenant. He had a job which involved going to the supermarket once a week (with his support worker) and collecting the shopping for an elderly lady, for which he was paid. His support worker commented that: 'he never makes any mistakes, never ... he loves his job ... every Tuesday morning he sits in the chair and we look at what we have bought, don't we.' The job was organised by an employment agency for disabled people. The support worker said that she had really had to push to get Edward the job. She also commented that the job had made a lot of difference to the elderly lady in question: 'Edward sends her a holiday card and a Christmas card ... and he bought her a present for Christmas and she bought him one'. The job, therefore, was not so much seen as of value as a source of income, but as a means of increasing social contacts for Edward and providing a purpose and structure to his life.

Sharon had been very active in tracing Edward's history and lost relatives. She had put together a 'life file' for him when she first started to work with him, three years previously. Edward's mother and brother Jo had visited him at his house about four years ago. Sharon felt that because the staff were busy they had not asked for his mother's address and telephone number. Sharon obtained Edward's birth certificate, visited the local library and looked up his mother on the electoral register. After some searching, Sharon located Edward's mother and brother on a nearby council estate. The family welcomed Edward and the support worker in.

Sharon arranged for Edward to visit his other relatives in various parts of the country. They went to Ireland to visit his sister, Zoe. When he was there his father telephoned, wishing to re-establish contact with Edward. Some photographs of Edward when he was a child with his grandmother, who had looked after him when he was very young, were given to him by his father. Sharon had collected photographs from all of the members of Edwards family who were in contact, and made them into a life file, giving names, times and dates so that they could be referenced easily:

'This is Catherine's (his sister) wedding photograph ... and these are her children ... it's really lovely for Edward to see these ... for all of us, it put Edward's life in context ... he's not just the young man who lives here, who has nobody ... he belongs, he has a history ... his grandmother adored him ...'

Sharon seemed to be an exceptionally dedicated support worker, who had put in a lot of time and effort tracing Edward's family connections and re-establishing contact. Edward began to see and to hear from family members regularly, and as Sharon noted earlier, he was given greater depth as a person through finding out about his past and identity. Like Philip, he was no longer seen as 'just a body'. Kin relations were re-established and his past contextualised. Edward had a job, albeit a very simple one, supported by his care worker, which is a factor in ascribing full personhood in British society. Mara voiced the opinion that even though Edward was quite profoundly disabled, when his story/biography was recounted to him, it appeared to have meaning for him. She judged this through his attentiveness and gestural responses, which were

obviously open to many interpretations, but the fact that he was seen as comprehending what was going on is important as it reflects Entelechy's conviction that all persons, regardless of their disability, are able to participate fully (albeit with assistance) in the lifeworld.

It is evident from the above case studies that the lives of people who have profound and multiple disabilities are controlled virtually totally by others, primarily paid carers. Often, this leads to a merging of identities between carer and cared for. This seems to occur because the profoundly disabled are very dependent for their basic needs on others, and rely on advocates to interpret and voice their assumed needs and desires. Because their 'self' is so diminished, they rely even more on relationships with others than the general population does, to make them into a 'person', and this process is highlighted when they leave institutions. Dependency on carers for social definition can become more acute if these are the only people with whom they interact on a daily basis. Some of the carers to whom I spoke in relation to this project seemed aware of this process of 'identity merging'. For example, during one of the training sessions, the carers discussed how staff often project their own personalities on to 'clients', dressing them in particular ways: 'You can often tell who has dressed a particular client that day' (carer). This was due to the fact that the clothes reflected the carer's own 'projected' personalities in their choice of colours, style, etc. Through the compilation of 'life books' by carers and other interested individuals, relationships are made tangible; although many such relationships (particularly those with paid carers) are not sustained. The informal documentation of these people's lives, however, appears to give carers the

ability to attribute the disabled person with a self, and, in some cases, to prioritise their client's needs.

These case studies are examples of the project's aims of 'action research', with care workers initiating the production of an 'auto'/biography/life book (as in the case of Edward), or following through with the idea after initial impetus from Entelechy. The rather fragmented and incidental format that these case studies took reflected the fragmented way these people's lives were often recorded and experienced. This is largely due to the high turnover of staff, loss of contact with kin, and the transition from institutions to *the community*, during which many records were lost or destroyed. It is left to paid carers to create and preserve evidence of the existence of the person in their charge.

Resulting from their experiences with the ROH project Entelechy suggested that procedures in tracing someone's past needed to be normalised. The cases where kin were traced and attempts made to reinstate displaced persons within kinship networks were received with mixed reactions. Some relatives traced through the project thought that the researchers wanted money: 'People were worried, in the light of "care in the community", that more responsibility would be asked of them' (Mara). Another concern raised by relatives was that the agency contacting them was looking to send their disabled relative 'home'. Some relatives also raised the question of 'why now?' There is circumstantial evidence that contact with relatives in the past, when the disabled people were institutionalised was discouraged: 'I think the hospitals didn't want families to be involved ... The families might question why their son or daughter

wasn't wearing their own clothes ... or why they had a scratch or a bruise ... people were encouraged to stay away' (Caroline- A local authority service broker and member of the RAP).

These individual pilot studies highlighted the processes involved in tracing someone's history, including the level of support needed from carers and managers. A common problem among care workers seemed to be finding the time to carry out research into their 'client's' past, as their time was mainly taken up with basic care activities and housework. Continuity of recording and storing information about a 'client' when a member of care staff leaves was another important issue, as the high staff turnover in the caring professions means that information often gets lost. This brings into focus several issues, including who controls information about a 'client', and how it is (or is not) disseminated. Additionally, the issue of 'risk' is important, as some care staff have restricted knowledge of potentially violent/self-destructive 'clients' due to information being withheld by senior management, on grounds of confidentiality.

vii) Crafting Our Memories

One of the major findings of the pilot stage of the project was the very real need for isolated individuals with learning disabilities to increase their social contacts, local connections, and leisure activities. As mentioned earlier, it was found that there was a strong desire among the former residents of Darenth Park Hospital (and Grove Park Hospital) to meet up with each other again after their relatively recent enforced separation.

Entelechy set up two groups which addressed this need. Firstly, a song and dance group for older people with a wide range of learning disabilities was initiated, called 'Old Songs and Afternoon Tea'. This took place at a local community centre, where a musician and a performance artist (Pam Martin), employed by Entelechy, facilitated dancing and singing of 'old' tunes from the first half of the twentieth century. This group was hugely successful and very oversubscribed, although the facilitators tried to fit in as many people as physically possible. In 1998/1999 the group was expanded on an occasional basis, and large 'Tea Dance' events were held in various venues, including a collaborative event in the Royal Festival Hall, London. Charles Hayward, (a musician) was invited to work at some of the bigger tea dance events, and wrote about the experience in a recent article:

There are these wonderful things called tea dances - which are exactly that - with storytelling, old songs, Flannegan and Allen songs, or songs from the First World War, played by all sorts of people. And I take part in that on bodhran or on spoons ... Then inside all of this there will suddenly be some improvised music from John [*a double bass player*], Ros [*a singer who has learning disabilities*] and me. What we do is very physical and all these elderly people really like what we do.

Charles Hayward 2000: 3

The second initiative was a group set up in September 1997 in collaboration with the Southwark Education Older Learner Project and the Time & Talents community centre in Rotherhithe, and was called 'Crafting Our Memories' (COM). This group engaged people with a wide range of abilities in creative work, and most of the non-verbal 'narratives' produced in the ROH project were accomplished here. Mara described the aims of this part of the project as attempting to engage in:

A qualitatively different way (from the verbal text-based life story approach undertaken in the individual pilot), with people's histories, identities or sense of self, and to establish arts-based activity informed by what can be broadly termed 'self as source' type of themes, on a regular basis.

(From Mara's Progress Report to Department of Health 1997-98¹⁵¹)

I attended this group as a participant observer for approximately twelve months. The developmental aspect of the project was aimed at encouraging non-contractual relationships; in particular those between people with learning disabilities, volunteers and other non-disabled older people from the local community:

There is a real development possible from people with learning disabilities, from how they may have perceived or experienced themselves in their long term residential hospital stay, to now becoming full members (of society) and ... adding a whole range of new activities ... new ways of being ... new interests and also new relationships which might reflect other parts of themselves that previously may have been invisible or not expressed.

Mara

Institutionalisation, therefore, was seen as having 'stunted' the inmates' personal development, and the return to *the community* meant that the development of the person could recommence. In the light of this, the craft group was set up as a session for 'older learners' (officially for the over 50s, due to the funding requirements from the Southwark Older Learners project). A session was held each week on a Friday morning. Initially Mara sent out letters to the homes where older people with learning disabilities lived within Southwark and Lewisham, inviting them to come to the group. Over the year, the number of people with learning disabilities in the group varied from between four and eight. The rest of the group was composed of Mara, myself,

¹⁵¹ See Appendix XII

volunteers from the local area, an art teacher, and care workers who accompanied their 'clients', usually making a total of between eight and fourteen people.

The craft group was set up with the aim of becoming an 'integrated' group of both able and disabled members, with participants operating on an egalitarian basis. Entelechy was very keen on the integrative element of the group, as they explained in a document produced at the end of the project: 'Data in Emerson *et al* (1999:9) illustrates that only 30% of learning disabled respondents had a person identified in their social network who did not have a learning disability, was not a member of their family and who was not paid to be with them.' (Slater and de Wit 1999:35). However, during the period of my fieldwork this kind of integration clearly was not achieved. There was a conflict of opinion between the art teacher and Entelechy as to just how egalitarian the ethos of the group should be. The adult education model defined people with learning disabilities as 'students'. Non-disabled people, who formed the majority of the group, were in the roles of carers, volunteers and teachers. A didactic model therefore came into being between the learning disabled 'students' and the rest of the group who were in a position of authority as teachers and care givers. Although an attempt was made to return the group to a more equal footing, the head of Southwark Adult Education thought that it was crucial that the group was 'happy' and 'working together' before they even thought about integration, thus implying that integration was a more complex goal to achieve. There was, therefore, a constant tension between didactic and egalitarian modes of interaction. Social interaction between the people with learning disabilities and others in the group was taken as a sign that the former were developing new competencies and becoming more enculturated within mainstream society, moving

towards autonomy and individuality and, by implication, full adult status. However, Mara felt that the people with learning disabilities had their own 'culture', and ways of acknowledging each other, which were different from the rest of the population, and this became noticeable in groups such as COM and the Tea Dances.

As explained above, attempts at integrating non-disabled people with learning disabled people were largely unsuccessful. The older women volunteers without disabilities who attended the group to help with art and craft activities, tended to keep to themselves, and did not interact with the learning disabled members of the group at all. An exception to this was Agnes, a woman in her fifties, who attended the group consistently throughout the first year of the project. She took on the role of making tea for everyone, saying 'that's what volunteers do, isn't it?' She therefore had a clearly defined role, marking herself out as a 'carer'. She said that she had volunteered at the Time & Talents centre because she wanted to feel part of the local '*community*', having recently moved to an upmarket apartment in Docklands. She interacted with the disabled group members to an extent, bringing them refreshments and sometimes helping them with their craftwork, but rarely engaged in producing her own artefacts. Vanessa, a young female art student who intended to train as an art therapist, also attended the sessions as a volunteer, and used the sessions to build up her own experience. She also, therefore, had a clear agenda of her own. She participated in the craftwork and social interactions with disabled people more than any of the other volunteers, often making her own artefacts alongside the disabled person. 'Integration', therefore, was measured not only according to participation in the activities of the

group, but also in the involvement of social interaction with the learning disabled members of the group.

During the first term of the project, 'life books' were made by all the members of the group, including some care staff and volunteers¹⁵². The 'life books' concentrated on identity and history, a person's past, real or imagined, made visual through art and photography. Through conversations with a 'helper', or in the case of non-verbal people, conversations between the helper and a close relative or carer, a sense of the identity of the person with learning disabilities was supposed to be built up. Creative actions by the learning disabled person involved would be incorporated into this process, for example paint marks or objects made from clay. In the case of non-verbal people, information gathered from observation of them by the helper was also used. Walter, who rarely spoke but played the piano, had his 'communication' through music incorporated symbolically into his lifebook, through the drawing of full-scale piano keys. The books included such things as 'memories' of relatives and friends, places where they had lived, activities in which they had taken part, employment if relevant, and things that they enjoyed or disliked. Through gentle questioning, information was gathered by the helper from the person with disabilities and/or their carers, and relevant points from conversations were written down either by the person with learning disabilities or the helper.

¹⁵² Carers and volunteers made their own books without assistance, although everyone shared in the creative process and showed each other what they had done.

In a very simplified, but profound way, random moments from the lives of people with learning disabilities were stilled through creative processes and reproduced in the group in non-textual ways, such as through paintings, collage or clay: 'These creative processes and textual practices stimulate access to past moments and experiential knowledge, retained through and triggered by the senses. They also produce objects and material evidence reflecting someone's past in the immediate present, as well as highlighting and marking personal, authentic environments' (Slater and de Wit 1999:29). Unlike many of the oral and textual narratives described previously, these predominantly non-verbal narratives were not usually episodic or sequential, but jumped about, rather like Barthes' 'Sadian novel' :

To recount, here, does not consist in developing a story and then untangling it, adhering to an infinitely organic model (to be born, to live, to die), i.e., to subject the series of episodes to a natural (or logical) order, which becomes the meaning imposed by 'Fate' on every life, every journey, but in purely and simply juxtaposing iterative and mobile fragments: then the continuum is merely a series of bits and pieces, a baroque fabric of odds and ends.

S. Burke 1998:37

Like *Roland Barthes by Roland Barthes*, where the author wishes to distinguish between the self he is writing about and the self that is writing, non-verbal narratives, consisting of visual representations, may be presenting a totally different self from the self which is creating them.

Under the direction of Mara and the art teacher¹⁵³, the focus of the group was on the material representation of aspects of their identities and pasts, concentrating on themes such as 'families', 'likes and dislikes', their previous locality and where they now lived.

Tom, a man in his eighties who had spent over 60 years in Darenth Park hospital, was able to communicate through speech in a limited way, and responded to questions asked about his life by the helpers in the group. He made a picture of the garden in which he used to work at Darenth. He drew lots of vertical rows of soil with green plants in them, and drew pictures of the tools he used. He was asked about other memories, and he talked a little about 'that place I used to live in - Darenth'. When questioned about his family, he said that he had three brothers and one sister. His younger brother used to visit him, although he died some time ago, but he had a niece who visited him 'now and then' and sent him letters. Tom was encouraged to make models of his 'remembered' family out of salt dough. In a later session, he described the house that he lived in with his family before he was taken into Darenth Park. He said that there were three flights of stairs, with one room at the back and the bathroom at the front. A helper took the words and phrases which Tom used and turned them into a text:

The family lived here for 17 years but they had to move because the rent was put up. So they moved to Deptford. The house wasn't so good. Tom had a smaller room, and other people lived downstairs so they couldn't play downstairs. Tom's dad lived next door.

At the time of this study, Tom lived in a house with four other older men from Darenth Park:

Now Tom lives in New Cross ... Tom has his own bedroom. It's a nice room, rather small. Tom has a radio, and a photo of his brother Brian. Tom has a cabinet and some drawers. The drawers are full of papers and books and letters. There is a window in his room, and outside he can see the road, the other centre and people gardening.

Interestingly, the helper decided to write the text in the third person. By supplementing Tom's drawings with text, the helper was translating Tom's experience into a genre to

¹⁵³ The art teacher was employed by Southwark Older Learners Programme.

which he did not have access, as he was illiterate. Issues arise such as what is lost in making stories mainly textual, and what is added by the facilitator¹⁵⁴.

The different case studies which follow illustrate several things, including the process of the production of material representations of 'memories', and the effect that participation in the craft group had on the people with learning disabilities in both personal and social terms.

Case study 1: Mike

Mike was a 68 year old white man, who had spent most of his life in Darent Park hospital. He now lived with two other older people with learning disabilities, Bob and Katie, in a shared house in *the community*, with twenty-four hour staff cover. Bob was non-verbal and Katie often locked herself in her room. Therefore, Mike had very little opportunity for communication with these housemates. He usually attended the session with one of his care workers, Alan, a 30 year old Zimbabwean man.

Subtle, but significant changes in Mike's behaviour were noted by his care worker, who discussed them during a review meeting held after Mike had been attending the Craft group and the Tea Dance group for a term:

When I first started working with Mike, if you told him to sit there, he wouldn't move ... He wouldn't do a thing, you could leave him for two or three hours ... but since he has started going to the groups he has found people who are on the same level as him ... I used to say, 'Mike we're going' and Mike would just get his jacket. But he is so assertive now, he's changed so much ... If he doesn't want to go, he'll say, 'No, I don't want to go out. I want to stay here'. (Alan)

Mike was perceived, therefore, as being much more assertive and able to make choices. It was also noted that he had started to engage in conversation with other members of the groups.

In his life book, Mike made an interesting picture of himself using buttons and beads to represent his joints and bones, as well as his penis.

¹⁵⁴ A similar dilemma arose for anthropologists who wrote down the stories of non-literate people who had an oral tradition .

All of Mike's earliest drawings of himself showed a prominent penis. It later transpired that he had been in hospital and had had a catheter fitted, and he was representing this in his drawings, as he found it difficult to communicate this fact verbally. There was very little text in Mike's life book. On most pages he drew a figure of a naked man, which represented himself. However, Mike was very prolific in his production of paintings and craft objects, and Mara commented that: *I think that he could fill the Hayward gallery in a few days ...*

Case Study 2: George

George was a white man in his late 60s. George spoke about his life, and created narratives, which were evidently a mixture of 'fact' and 'fiction'. For example, he told the others in the group that he was a 'man of means', and that he had a lot of money. During one session he had said that he used to be an engineer in a factory, making screws, etc. He also said that he had spent time in the RAF. None of this turned out to be actually true. He had spent the majority of his life in Darenth Park. George wished to 'pass' as a 'normal' person, denying his connections with the institution. Making up a past was a completely reasonable strategy for dealing with this situation.

George liked to walk home from the craft group, rather than take the bus. He seemed to enjoy conversing with Mara and myself, and looking at things in the park. On one occasion, he got out his (free) bus pass on arriving at his home, and gave it to one of the support workers for safe keeping. He announced that he wasn't stupid, and that 'I walked to save money, so I didn't have to pay my bus fare'. He said to me 'I'm not stupid, am I?', to which I replied, 'no'. The support workers seemed amused by George thinking that he had saved money. Mara tried to explain to him that his bus pass was free anyway, but he didn't appear to understand this¹⁵⁵. George spoke about his family to the art teacher. She wrote down in his life book his responses to her questioning:

George remembers playing with his toy train, which ran on rails and had a paraffin burner inside it. He played with his brother, Johnny, and his sisters, Mary, Helen and Elizabeth. Elizabeth died recently, but George didn't want to go to the funeral. George still sees Johnny, Mary and Helen. They all live locally. They all went out to work. Johnny is married as are Mary and Helen. Elizabeth never married.

¹⁵⁵ This incident can be compared to the research carried out by Edgerton (1967) who looked at the lives of people with learning disabilities who had recently moved into *the community*. These people constantly sought reassurance that they were not 'stupid', even though their actions often led to a questioning of their competence.

George did not in fact have contact with his brothers and sisters. He was part of the pilot group whose histories were traced. When his brother and sisters were contacted they said that they did not want any contact with him as they found it too upsetting. As he had spent most of his life in an institution he had not had contact with his family for many years. He created a fiction of family life in response to questioning, which indicates that he was completely aware of what a 'normal' person's life should entail. In later sessions, George made models of members of his family. Later on in his life book, George talked about his 'memories' of Christmas, which the art teacher had written down on his behalf:

George and I are talking about Christmas, and his memories of Christmas as a boy. George remembers being given a teddy bear when he was ten years old, which he called George. He also remembers being given a black toy car when he was twelve years old. He remembers taking toys off the tree.

There was no reason to suppose what George had just said was anything other than fact, although it may again be an example of how he was trying to 'pass' (Goffman 1963), creating a 'normal' fantasy life.

George suffered from severe depression and stopped coming to the group after the first term, preferring to stay in bed. It was difficult to assess what impact his involvement in the project had on him, and whether in fact, the unsuccessful reunification with his family had actually had a detrimental effect on him. This issue and the whole ethos of the project was brought into question during a meeting near the end of the first year, when whether or not professionals and carers had the right to try to help people 'rediscover' their histories was discussed.

Case Study 3: Sheila

Sheila was a white woman aged 60, but who said that she was 47. She appeared to be the most able person in the group. As well as having a learning disability, she had mental health problems. She had her own flat, with support workers who came and visited her. She used to live in a shared supported house, but expressed a wish to live on her own in a flat, and she achieved this in 1997. She dressed in bright clothes, and wore lots of jewellery. She carried many objects around with her in a plastic bag, including a china dolphin and lots of religious icons, rosaries and crosses. She said that she was Catholic, like her parents, and that she went to Church every Sunday. In the sessions she drew a lot of religious imagery such as angels, and the Virgin Mary. Sheila had quite strong kinship relations in that she visited her sister once a week, and had frequent contact with her brother. She was in a 'mental handicap hospital' for a few years, but was taken out by her family to care for her

dying mother. Sheila often commented that she had no 'mum or dad', seeing this as a reason to pity her, despite her being aged 60. Through such comments, Sheila was reinforcing the cultural idea of learning disabled people as dependent and childlike. However, she used this to her own advantage, manipulating her perceived dependency to gain attention and sympathy.

Sheila was aware that she was 'different' and that she had been classified as having a learning disability. She referred to her mental health problems as her 'nerves', using this as the reason for her emotional outbursts and temper tantrums, when she became verbally aggressive to other members of the group. She made a distinction between 'inside' and 'outside'; that is the private and public domains. In private, it was all right for her to express herself how she wished, and do things like put fresh flowers in her hair. She felt able to be friendly with black people when she was 'inside'. However, when she was in the public domain, she became very self-conscious. She became very hostile to black people, frequently abusing them verbally, and convincing herself that they were going to attack her. Far from being a symptom of mental illness, I suggest this was a coping strategy that Sheila adopted to help her deal with difficult and ambiguous situations. She was very much aware that she was a stigmatised individual, and was able to manipulate her identity in various situations. For example, she emphasised her 'incompetence' in order to excuse herself from blame when she was in confrontational situations, although, in fact, she was actually very aware of what she was doing. She was not very tolerant of aberrant behaviour from other members of the group. For example, Doris, a woman with profound and multiple disabilities who joined the group later in the year, deeply disturbed Sheila when she called out loudly and continuously during the sessions. Sheila asked whether Doris could be given some drugs to 'shut her up'. As I describe below, Sheila was able to empathise with the suffering of others if she converted it into her own experience, making it part of her own narrative. However, she had difficulty empathising with those whom she perceived as a threat, especially if they were getting more attention than she was. In these instances, she turned them into the objectified other, incompetent in the light of her own self-perceived competency.

In January 1998, a documentary film maker visited the arts and crafts group. This new audience provoked Sheila into being very verbal throughout the session. At the beginning, she became very emotional, saying that her sister was in hospital, and 'I ain't got no mum and dad ... you wouldn't like it if you ain't got no mum and dad'. She said she thought the group didn't like her. This was met with reassurance from one of the volunteers. She then launched into a narrative about her life in an institution. She said that she had been in Darenth Park, (in fact, she was actually in a different institution), asserting that she was there

for 12 years, although in reality she was only there for shorter periods of respite care. An advocacy worker who knew Sheila well later told me that a lot of things which she said were fiction mixed with fact. Sheila was a member of a drama group ('Through the Door', also run by Entelechy) which had engaged in reminiscence work. Many of the members of the group had spent long periods of time in institutions, and Sheila had incorporated their experiences into her own to great dramatic effect. In contrast to George (described above) Sheila viewed being institutionalised as presenting her with secondary gains, such as attention, sympathy and a ready audience.

For Sheila, involvement in the group allowed her to increase her social contacts, and reinforce existing ones. For example, Olive, an older woman whom Sheila had known for a long time, and who was similarly able to live semi-independently in *the community*, reaffirmed their friendship during the craft group, and they often exchanged paintings with each other. Involvement in the craft group and other Entelechy groups (namely the tea dance and a drama group), gave Sheila the opportunity to make regular social contacts with other people with learning disabilities whom she had known in her past, and also to test the boundaries of socially acceptable behaviour. Sheila was therefore able to achieve a 'viable' self through her embeddedness within this newly invigorated social network. Her experience as one of the most able people who have been classified as having learning disabilities has resonances with that of Nancy Johnston and Harry Black, referred to earlier. Sheila was evidently very skilful at presenting her narratives (which were a mixture of ontological and public narratives), tailoring them to suit specific audiences. She was clearly aware of how the general public perceived people with learning disabilities, and took advantage of this perception.

The ROH project received local and national recognition. At a local level, three members of COM were presented with 'Adult Education Achievement Awards' by the Mayor of Southwark. It was felt that the award ceremony had been an 'integrated' event. There had been a large mixture of people from different backgrounds, including refugees, ethnic minority groups, people with disabilities and 'lots of ordinary people'. The COM members had invited neighbours, family and other carers. Photographs were taken, some of which appeared in the local press, much to Sheila's evident enjoyment.

In order to accept their awards (with which they were clearly very pleased), the COM members had to cope with the ordeal of moving through the audience on their own: which they did to rapturous applause.

vii) Conclusion

Narrative in its many different forms, as illustrated above, can present a vehicle through which to gain some semblance of a culturally embedded self. Entelechy's ROH project, I suggest, had the intention of restoring the 'mortified self' post institutionalisation, and reinstating social and kinship networks on re-entry to *the community*. However, in many cases, this was problematic. For example, Goffman asserts that some roles can be re-established when an inmate returns to the outside world, but in many cases a kind of 'civil death' has occurred during the process of institutionalisation. People who have learning disabilities and who have been institutionalised for most of their lives have missed out on many 'normal' life course events such as education, heterosexual relationships, marriage, parenthood, and the creation of a sense of identity through employment¹⁵⁶. On re-entering civilian life, the effects of having been in an institution continue. For example, many people would be unable to start a family as they were too old. They would usually be reliant on state benefits, as they would not have accumulated any money or a pension during their lives, and consequently would have a

¹⁵⁶ This is not to say that people in institutions did not work – many were forced to work, doing hard manual labour on hospital farms, working in the hospital laundry, or doing domestic work. However, the inmates received little or no pay, had very little choice in what they did, and as they were working

low standard of living. Attempts to restore their personhood may be well intentioned and commendable, but it is not easy to compensate for a lifetime of sequestration or abuse, and many social and cultural barriers still exist which prevent people with learning disabilities from re-establishing their lives in *the community*.

However, what arises from an examination of the effects of the project is that firstly, there exists among older people with learning disabilities a very fragile culture, some of which is residual from their previous institutional life. Particularly among those seen as 'less able' or those who communicate little through speech, this culture seems to exist in the silences and quiet acceptance of each other. In order for their stories to be told to a wider audience the language of the majority must be used. It is inevitable therefore that many things are lost in the process of interpretation and by the methods used to structure and record such stories. The ROH project attempted to access directly this fragile culture, much of which was intangible, through creative means. This attempt appears to be a definite step in the right direction for greater appreciation by the mainstream culture of this marginalised group's lived experience.

The various aspects of the project seemingly achieved the most positive outcomes when they enabled participants to create 'real' or 'imagined' relationships with other people, making their 'selves' in the process. Sheila's case study is a particularly pertinent example in this regard as involvement in COM (and other activities with Entelechy),

within the economy of the institution, were unable to separate out their working role from the rest of their lives (see Goffman 1991).

increased her social contacts considerably. A bolstered sense of self was achieved in her case through the construction of a network of 'significant others'.

The ROH project highlighted the complex issues around learning disability narratives, particularly with regard to notions of 'fact' and 'fiction', and 'for whom' such narratives are produced. The textual narratives which I explored first, were, as far as it is possible to know, 'factual'. As I have stated earlier, they were written or dictated by people who were articulate and aware of the stigma of having been labelled 'mentally handicapped'. There was a general wish to produce fact based accounts of their lives, which were credible, and to describe to others the injustices and abuses to which they had been subjected. The narratives produced in the pilot study were mainly written by care workers, who had collected information from as many sources as possible. They were not therefore first hand accounts, and were vulnerable to imposed interpretations. Also, as the subject of these narratives was often non-verbal, they were unable to correct details or fill in gaps. These narratives, therefore, were more fragmented than those written as first hand accounts, and parts of the subject's life were left as blanks. This does not make them any less credible, but does give the impression of an incomplete past/history, which implies an incomplete self. The non-verbal narratives, or visual narratives, were, by their very nature, a mixture of fact and fiction, as they were mainly produced by or for people who had a lot of problems communicating verbally, and who were not able to give a coherent sequential account of their life. Often the members were prompted to draw particular things by the art teachers, such as pictures of their family. Many people could not remember their family and made up fictional ones, which may indicate a desire to please others, an observation that has been noted

by other researchers. It may also illustrate that most of these people were deeply aware that they were perceived as 'different' from 'normal' society. Fictional representations may also indicate a life which was desired but not attainable, for example having paid employment or owning a pet.

In contrast to the slave narratives, Entelechy allowed a free reign to the member's imagination, and fiction was recorded alongside 'fact' as an equally valid representation of the narrator's newly reconstituted self. I questioned Mara about whether or not she thought that it mattered if no distinction was made between truth and fiction. She replied that it depended on the purpose for which certain stories were reconstructed or retold¹⁵⁷. In a subjective account of a person with learning disabilities, it was felt that it was possible that any fiction or elaboration could actually reveal parts of that person's true personality.

When memories become embodied and a person switches from one time frame to another, often triggered by an imperceptible event or action, there can be a further blurring of 'fact' and 'fiction'. For example, Doris, an elderly woman who joined the group later in the year, verbalised a whole dialogue during most of the sessions she attended, which centred around her experiences in an institution. She would say repeatedly: 'She hit me, she did. I don't like her. I'm going to tell matron'. Some of the disabled members of the group became distressed by her outbursts, thinking that she was accusing them of hitting her. Doris was, in fact, engaging in a dialogue from her past, while simultaneously carrying on with her craft activities in the group. 'Fact' and

‘fiction’ therefore became blurred: no one was hitting her in the present, but she was reliving a very real experience from a different time frame. This is an example of an ‘embodied narrative’, where memories are triggered by present events leading to the reliving of the past both physically and mentally.

It was felt that it was essential for those running the group to realise that they were working with people who had been held and kept in very restricted roles historically. Even though they were older people who might only live for a few more years, Mara believed that they held a great potential for development. The role of imagination in creating a past and an identity for oneself was acknowledged as an important factor:

Development belongs in the territory of taking and occupying different roles ... not being just the person with disabilities being cared for, looked after, cleaned up, wiped up ... I think it is in that territory that we are at work.

Mara.

Entelechy, therefore, saw this group, and the project as a whole, as a vehicle for restoring personhood, at the same time as breaking down and analysing the roles of carers and professionals, and reassessing what it meant to be human. It was suggested that it was really all right to mix fact and fiction in learning disability narratives, and that ‘certainly the intention is not to make a therapeutic journey to the soul. You can sense when people want to leave things out, or not touch on subjects, or in fact make up fictitious lives’ (Mara). However, Joy (an art teacher employed by the Southwark Older Learners’ Programme) argued that a therapeutic journey was certain to happen in this sort of environment:

¹⁵⁷ See Appendix XIII

Even if you don't call it a therapeutic journey ... to set up a project like this, that's what it is ... when you're using art and creativity ... and you're talking about where the members have come from, and their past, and their family, and their dog ... and friendships ... it's not just an arts and crafts group ... they're using arts and crafts ... but they're not really creating a little teasel dolly or an apron ... they are going much deeper than that.

Yet again, the issue of where the boundary can be drawn between art and therapy was raised. Entelechy's approach, as I have discussed elsewhere, was to see the creative activity, the aesthetic experience, as primary, and any therapeutic outcomes as secondary and almost incidental. Members of Entelechy did not profess to be therapists, but obviously, as Joy had pointed out, embarking on reminiscence work with a group of individuals who, almost unanimously, had had deeply traumatic life experiences, certainly raised issues to do with emotional support, therapeutic intervention, responsibility and confidentiality. These, and other salient issues raised in the thesis will be discussed in the concluding chapter.

Chapter Eight

Conclusion

The study of non-Western (non-white) people 'expresses a certain will or intention to understand, in some cases control, manipulate, even to incorporate, what is a manifestly different (or alternative and novel) world (Said, 1995: 90). The same ethnocentrism can be found in certain individualising approaches to the study of disability. Many of the 'humane' solutions to the 'tragic' lives of disabled people represent a colonising of experience. The definitions of personhood which form the basis of theories of citizenship often exclude disabled people.

D.Marks 1999: 28

It has been argued that it is not the impairment but social isolation and lack of support which makes some lives unbearable. The assumption that certain impairments automatically lead to an unacceptably low quality of life is not rooted in an accurate understanding of the experience of impairment. Rather, it represents a failure of imagination and the pathologisation of disabled people.

D.Marks 1999:41

i) Final Reflections

This thesis has addressed a unique cultural experiment, operating at the juncture of social policy and lived experience. Entelechy's use of 'the arts' as a communication channel and arena for emotional and political expression by people with learning disabilities has been documented. The effectiveness of such 'cultural intervention' has been brought into question, as has the extreme difficulty of measuring such effectiveness in this particular arena. In their workshops/performances, I suggest, Entelechy created situations of 'antistructure' (Turner 1994) where people who deviated from the mainstream of society could interact with professionals and their non-disabled peers, creating new platforms for social engagements which would not normally happen in the course of everyday activities. These 'liminoid' (Turner 1969) spaces were utilised to experiment with new forms of communication between disabled and non-disabled

people, which, in turn, could be used to influence interactions and engagements in wider society. The phenomenological space in traditional theatre between the spectator and the performer was renegotiated in much of Entelechy's work to bring about a situation where both parties were interchangeable, and in which the categories of disabled and non-disabled could be rearranged and played with, creating provocative dialectics between the perception of 'normality' and 'abnormality'. However, the impact of such activity was limited due to the relatively small number of people taking part, and the various social and material obstacles in place. For instance, funding for projects had to be renegotiated continually and the small but real improvements made in the lives of some participants could be negated by lack of continuity. It seems important to view the work of Entelechy as having political potential when it took on its most radical and experimental forms, at the same time as heightening the awareness of cultural differences and focusing on the body as 'social text'. Entelechy's experimental work, the outcomes of which were not easily predictable, could be seen as a type of 'emergent' cultural practice (Williams 1977); thus concurring with the suggestion that: 'In part ... the possibility of new social orders lies in reading the struggle between the dominant ever-present normalising tendencies and properly emergent cultural elements' (Fulcher 1996: 185).

Such 'cultural intervention' exists on a 'knife-edge' between resisting and being incorporated into the status quo. Entelechy's work encompassed two rather different movements. The first is the disability arts movement, which has a radical political agenda, stressing 'the importance of the arts in developing cultural (and by inference political) identity ... exposing the disabling imagery and processes of society. There is

also a role to play alongside conventional political activities' (Barnes et al 1999: 206). Disability arts are potentially transformative, a form of cultural action which is 'radical, challenging and progressive at an individual and social level' (ibid.), attacking dominant meanings in contemporary culture; creating new aesthetics; developing a 'disabled identity', as well as being 'a critique of dominant forms of cultural representation and production' (ibid.). The second movement is less easy to define, but involves several strands of social activism, which at times may be conflicting. These include (often nominal) adherence to the social policy of *normalisation*, at the same time as acting as advocates for 'the oppressed'. The very real difficulties of the life situations of many people with learning disabilities are acknowledged, including material and social factors, as well as a recognition that they may be in actual physical pain. This social activism, involving 'cultural intervention', was the role which Entelechy took upon itself, while at the same time trying to maintain the political agenda of 'disability arts'.

In recent decades, the disenchantment of many social and cultural activists with 'left-wing' or 'liberal' politics in addressing the issues of social polarisation, particularly the increasing gap between 'rich' and 'poor', has led to them turning to: "community politics as a new alternative' (Robson 2000:3). This has led to the emergence of 'a new political correctness ... in which community rather than class became the motor for change and in which energy emanated from the 'new' community worker rather than from the 'old', 'class-conscious' socialist' (ibid.).

Robson asks whether *community* action is, in fact, useful to the dominant order, as a valuable way of 'drawing local communities under the influence of the prevailing hegemony' (Robson 2000:9). He suggests that: 'The radicalism of the community worker, acting as organic intellectual, dissipates under the weight of state supervision. In those circumstances, therefore, the emergence of a counter-hegemony proves unlikely and the community "movement" emerges as a principal agent of the dominant ideological hegemony' (ibid.). With this in mind, therefore, the effect of the involvement of Entelechy in the lives of people with learning disabilities, either at an individual or societal level, must be considered. If viewed as part of the post-war counter-cultural movement and alternative theatre, such practice possibly contributed to 'progressive changes in the dominant culture, forcing adjustments in the general social and political order' (Kershaw 1992: 8). On the other hand, however, Kershaw more pessimistically suggests, 'alternative theatre and the counter-cultures may have been simply absorbed into the dominant order through a process of repressive tolerance which effectively neutralised their oppositional ideologies and reinforced the status quo' (ibid.). Fulcher has asserted that government rhetoric concerning people with disabilities and their actual lived experience, rarely converges: 'The ideas of policy, programme, implementation, objectives, outcomes provide a rational reading of a deeply political reality. The reality is different: it is that of struggles, contradictions and dilemmas. Thus this reading of cultural and political life requires a quite different set of ideas from those that government proffers'. (Fulcher 1996:185). It is precisely at this juncture of policy and 'lived experience' that Entelechy aimed to operate.

Entelechy attempted to get within the mainstream aesthetic and change it, underlining the inherent ‘ordinariness’ of disability, while at the same time seeking to combat ‘normalising tendencies’. In their work, particularly with people who had profound and multiple disabilities, the non-disabled performers were, to a large extent, ‘advocating’ on behalf of the disabled. They acted as mediators between the disabled performer, and the real or imagined audience. Where no spoken language was involved, it was particularly ambiguous as to what exactly was being communicated to the ‘audience’ (if there was one). It is quite possible that the majority of the ‘performers’ with multiple disabilities may not have been aware of the presence of an ‘audience’, or even that they were actually ‘performing’. What Entelechy achieved, however, was the opening up of the *possibility* of communication.

This research has demonstrated, through an examination of Entelechy’s techniques such as ‘contact improvisation’ and ‘soundscapes’, the possibilities for enhanced communication with people with learning disabilities, particularly those who have profound and multiple disabilities and who do not use any recognisable form of verbal or signed communication. The intersubjective attribution of ‘emotions’ between able bodied and profoundly disabled performers (e.g. in contact improvisation) is a contentious issue, and frequently can be seen as highly subjective. However, by opening up a more ‘embodied’ approach to such communication, new directions in understanding can possibly be achieved. Through attributing the people they worked with with ‘intent’, Entelechy emphasised the common humanity of people with learning disabilities, and attributed to their lives a higher degree of dignity than they had previously experienced. This was clearly shown in chapter 7, where many relationships

between carer and cared for have been enhanced as a direct result of engagement with Entelechy's projects. If, following Gorz (1973) 'transformation is a cultural task and a matter of small reforms' (Fulcher 1996:184), Entelechy's work can be seen to have had a considerable impact.

The displacement or elimination of the audience function by Entelechy allowed mainstream aesthetic views to be refocused, together with the idea of 'competency' in performance. The audience/performer divide was frequently displaced physically on to the performance area (the mats), allowing the relationship between participants to be less prescribed, and allowing for a much greater flexibility of roles. Entelechy utilised aesthetics to express emotion outside of therapeutic paradigms, which was one of Entelechy's major agendas. Raw emotion was seen as a creative energy and act of communication, displaying a primal consciousness which 'artists' had the skill to tune into. The concept of 'the drone', a trance-like state where thought patterns could be let go of and where skill was no longer an issue, was a 'new aesthetic' which was utilised to create a meeting ground between verbal and non-verbal worlds. 'The drone' could incorporate accidental incidents, but it also entailed 'nothingness'. In theory, 'the drone' highlighted the dependency on others for one's recognition of self, with intersubjective and intercorporeal states being reached by all participants. Partly through the drone, but also through other techniques such as 'mirroring', Entelechy tried to shift the locus of 'performance' from being viewed to being used, involving a reorientation of the senses in both disabled and non-disabled participants. Transformations occurred through re-embedding the aesthetic within a multi-sensory

approach, moving away from visual paradigms. Entelechy aimed to re-embody the perceptual experiences of all participants.

The artists and non-disabled participants were able to describe such experiences in words, but what was actually felt by those with profound and multiple disabilities was subjectively attributed to them by other participants. It was believed by Entelechy's facilitators that emotions were locked into the body and could be released through creative work. The movement away from traditional cultural modes of communication, and a relinquishing of roles, challenged the ways in which medical and social services treated such people, and could be seen as in contravention to *normalisation* policy, as the aesthetic is not culturally normative. Through challenging the boundary between 'performance' and everyday life, 'liminoid' spaces for experimentation were created.

An important element raised in this thesis has been the recognition and stimulation of a (fairly localised) 'culture of learning disability', reconnecting, invigorating and embedding relationships between previously scattered individuals, many of whom had spent years in asylums, and had been separated from life-long friends ('significant others') through the change in social policy towards 'community care'. The question is raised as to whether or not such a phenomenon is indicative of a legitimate sub-cultural group, with their own communication system or language. If such a sub-cultural 'language' exists, is it capable of challenging the dominant language? The speech patterns discussed in Chapter 6 (e.g. echolalia; culturally 'inappropriate' usage of the language of 'grief', etc.), rather than being seen as 'pathological' can be interpreted as indicative of a 'sub-culture' of learning disability, useful as a powerful form of protest,

and thus meeting participants' needs. Through creative media such as poetry and drama, (facilitated by Entelechy), these speech patterns can be validated and communicated to a wider audience, legitimated by being 'framed-as' art. Such a 'sub-culture', as indicated in chapter 7, is largely context specific and often extremely fragile, open to being subsumed within dominant discourses. What the 'cultural intervention' of Entelechy did appear to achieve, was to allow this 'sub-culture' to exist, albeit fleetingly, in their workshops and happenings. This was most clearly achieved when the people with learning disabilities were allowed to control the action and interactions. This began to happen as the COM group became more established, permitting a looser structure:

You find yourself in a different type of atmosphere ... there is a different set of values at work which actually ... have always had a very positive effect for me ... there is more room to be, people can trip over, fall, laugh, make mistakes, things don't work according to conventions, it becomes almost subversive, anarchic, but there is an enormous amount of room and different gradations.

Mara de Wit

In many ways, permitting and encouraging this 'culture' runs in contravention to the policy of *normalisation* which governs so much of the lives of people with learning disabilities. Rules of social interaction are subverted, and each other's 'incompetency' is accepted. Additionally, the existence of such a sub-culture suggests that the 'Western self' does not need to be 'coherent' in order to be recognised by others. Giving space and time to fragmentary recollections and experiences embedded within a 'sub-culture' of learning disability (albeit on a very localised level), highlights how easy it is for such a 'culture' to disappear, and at the same time bears testimony to the resilience of such 'oppressed' individuals in making sense of their lives, with or without 'cultural intervention'.

Some of the aesthetic techniques which were developed by Entelechy in order to interact with people with learning disabilities (including people with profound and multiple disabilities) in a meaningful way, could be expanded upon and utilised to further access the lived experience of this group. The use of 'contact improvisation' has been documented, a practice which it is believed heightens feelings of intersubjectivity and intercorporeality, allowing communication at an embodied level between people of very differing abilities. This technique, in theory, moves beyond any therapeutic dialectic, and allows a questioning of roles. When combined with music, the 'new aesthetic' which Entelechy developed, that is, 'the drone', allowed for the containment of 'abnormal' behaviour and the expression of emotion. This was achieved through practices such as 'mirroring' the movements and echoing back the sounds of the profoundly disabled, thus reaffirming their existence. Actual changes in behaviour and bodily posture have been documented which were interpreted by Entelechy as the result of the individual concerned 'choosing' to move rather than being coerced, as they might be in physiotherapy. The 'new aesthetic' cordoned off and incorporated alternative views of habitus, 'tuning in' to another person's consciousness through the body.

Entelechy's aims of easing the transition of people with learning disabilities from institutions into *the community* could be seen to be achieved to some extent, most clearly through the work of the Rediscovering Our Histories project. For many individuals engaged in this project, new competencies in expressing themselves, often

through the medium of art, were developed. These competencies, including increased confidence and social skills, could be seen to expand into other areas of their lives, improving understanding by others of their needs and desires.

A major accomplishment of all of Entelechy's projects was the building and reinforcing of social networks. This could be seen on many different levels. The projects introduced a large range of people with learning disabilities to each other, many of whom shared institutional pasts, and some were reunited with old friends. Others, particularly some of the more isolated younger people, were able to meet up with their peers in contexts which were fairly loosely structured and experimental. Care workers who engaged in the projects were able to develop new kinds of relationships with their 'clients' in the workshops. This was particularly evident in the arts and craft group, COM, where care workers could create their own works of art, while their 'client' was being supported by members of Entelechy or volunteers. The workshops also provided the opportunity for care workers to talk to their counterparts from other services or charities, resulting in a sharing of experience and a decrease in isolation. What the research has highlighted is that 'the self' in the Western cultural context is realized through personal relationships, with the lives and experiences of people with learning disabilities throwing this into relief: their often diminished personhood showed clearly the effects of being disembedded from kinship and other social networks.

Taking a Foucauldian stance, the study of 'abnormality' reveals much about power relations within a society. The inclusion of an historical review of the lives of people with learning disabilities near the beginning of this thesis sought to highlight some of

the origins of the dominant discourses which continue to influence the lives of this sector of the population. Dominant discourses such as ‘rationality’ and ‘normality’ can be seen to have been challenged through the participation of people with learning disabilities in aesthetic activity. It has been argued that *normalisation* is a hegemonic discourse, encapsulating the struggle between the disciplines of psychology and medicine for primacy in this field.

Entelechy’s aim was to move beyond *normalisation* to create a more radical and egalitarian practice, which was less oppressive to people with learning disabilities. Some of their practice tried to incorporate what they felt were the more positive aspects of this theory, particularly referring to John O’Brien’s five principles in the ROH project. It has been shown that the policy of *normalisation* is tightly bound up with the discourse on rationality, creating a very powerful ideological tool which perpetuates the division between ‘normal’ and ‘abnormal’, both in terms of behaviour, and the categorisation of persons. Cartesian theory, which pervades Western cultural ideas, was shown to heavily influence the treatment of people with learning disabilities. People with impaired ‘intellects’ are, according to this philosophy, governed by ‘the will’, and unable to perform self-control. As discussed in Chapter Three, ‘rational’ individuals in ‘community care’ (e.g. social workers) now take on the role of the ‘intellect’, whereas previously the intellect took material form in the guise of the walls of the institution.

The role of ‘therapy’ in the lives of people with learning disabilities has been shown as an endeavour to make individuals displaying deviancy function in a normalising society, e.g. realigning their bodily habitus to be congruent with the rest of the population; or

sanitising 'deviant' speech. In moving away from therapeutic paradigms, Entelechy's practice aimed to accept and incorporate different modes of habitus, rather than normalise them. However, changes in the disabled person's posture which could be seen as positive (that is causing them less pain) were welcomed by Entelechy, but, as noted earlier, these changes did not form the focus of the activity.

The ethos underlying Entelechy's work - that is, achieving a sense of 'relatedness' between people of extremely different capabilities - permeated all of Entelechy's practice. This 'relatedness' fleetingly took form in the workshops, but often spilled over into everyday practice in care homes and occasionally day centers. At the same time, Entelechy was committed to improving the 'quality of life' of all of the people with learning disabilities with whom they came into contact. Several of the chapters, particularly chapter 6 (the introduction of massage into Gail's home environment) and chapter 7 (Philip's enhanced home-life), have shown that, at an individual level at least, tangible improvements could be seen to have occurred in the 'quality of life' of some of those involved with Entelechy. Literature on 'quality of life' exists predominantly within the discipline of psychology. Jahoda has asserted that many people with learning disabilities are well aware of their situation and that they desire greater freedom of choice on how they lead their lives and construct their identities, as is demonstrated in chapters 6 and 7. Research by Barry, Crosby and Bogg (1995) suggests that: 'subjective assessments and objective assessments of the quality of life of people with mental illness living in long-term hospitals differed to a considerable degree' (Markova 1995:202), leading them to question the validity of 'subjective' measures of 'quality of life'. An anthropological perspective on 'quality of life' for people with learning

disabilities is useful, which acknowledges the fact that it is impossible to be purely 'objective', accepting the validity of the 'other's' reality. It becomes apparent, therefore, that the relationship between 'the individual' and 'society' is at question. Who is responsible for deciding the criteria of 'quality of life' for people with learning disabilities? What is the benchmark against which 'quality of life' is decided within a particular culture/society? In Europe and the United States, *normalisation* theory is almost universally used in the assessment of the 'quality of life' of people with learning disabilities', thus reinforcing the State's hegemony in the cultural (and economic) production of 'valued lives'. Entelechy's work has, to a limited extent, been effectual in extending the parameters of experience beyond *normalisation* in some of their experimental activity, particularly that which involved those who directly cared for the individuals with learning disabilities (e.g. Ambient Jam, and several 'happenings'). One of the main achievements of Entelechy's work, therefore, which has been identified throughout this thesis, was to bring into question roles and relationships, specifically between carer and cared for, creating a space where, perhaps, new ways of interaction could be achieved

It was also necessary to employ new methods of conducting my research, whilst endeavouring to be as objective as possible. Various participants, including those with very profound disabilities, often gave me fleeting insights into their kaleidoscopic and shifting realities, through our mutual engagement in creative activity. During these interactions, I attempted to extend my research techniques beyond the purely oral and textual. Visual media such as paintings and sculptures, and embodied media such as dance, movement and sign language all helped me to gain insights into the participants'

lifeworlds. In addition, Entelechy had developed methods for communicating and recording experiences of people with profound and multiple disabilities, using sensory techniques and non-verbal arts, which I observed and learnt from them. Partly because there is no culturally recognised way of communicating with people who have learning disabilities, specifically those who are non-verbal, a meeting ground has to be rebuilt during every encounter.

Very few people know the augmentative communication system of Makaton, which some learning disabled people use, and even within the services I did not see this system used with any consistency. The main way of understanding the needs and wants of a person with profound and multiple disabilities appeared to be to know them intimately, interacting with them on a daily basis. In my research, I encountered many relationships between specific care workers and their clients which enabled a high degree of interaction with, and participation in, the client's lifeworld. Many such relationships were, however, highly individual and the communication idiosyncratic on the part of both carer and client. Also, due to the high turnover of staff in this sector, many valuable relationships were often lost. It was very frustrating for both the 'clients' and those who worked with them to continually go over 'old ground'. Some of Entelechy's projects, particularly ROH, addressed this problem of continuity, through the development of 'life books', documenting the needs and desires of the person concerned. This approach was taken up by at least one of the statutory services during my research, and was disseminated at a national level through Slater & de Wit's publication of a training pack.

A further related issue is that of the 'aesthetic value' of the work produced in the workshops and happenings. As has already been suggested in earlier chapters, a focus away from 'product' towards 'process' in creative activity allows more possibilities for the expansion of aesthetics which can include people with learning disabilities and profound and multiple disabilities. Entelechy's work aimed to move away from rehabilitation, and the obsession with 'cure' which sustains ideas of sickness and dependency. Focusing instead on corporeality and the performing disabled body, challenges the aesthetic of oppression which underwrites the medical gaze. Aesthetic strategies were employed through which spectators became aware of themselves. Peters' view of 'disability culture' as personal/aesthetic 'addresses decoding or recentering as an essential development of cultural identity'(2000: 594). This view reconfigures 'disability' as subject, constituting the 'performative self, which is strategic and positional'(ibid.: 596).

The ephemeral nature of Entelechy's work allowed for a high degree of experimentation, but could be criticised for evoking 'new possibilities' in the lives of people with learning disabilities which could not be sustained in the medium or long term without continual input from an outside agency such as Entelechy. Controversially, Entelechy assumed that it was possible to build a sense of *community*, despite being based in an area of deprivation. They had an underlying belief in 'community spirit', although they conceded that it was difficult to define, and were sceptical about the existence of *community* in 'community care'. Their optimism was, to an extent, based on experience, as tangible networks of people engaged in artistic practice with people who had learning disabilities in this area of south-east London

could be discerned. This was, perhaps, the result of long-term cultural intervention in the area (starting in the 1970s with the Rotherhithe Theatre Workshop). What seemed to arise from this activity was the ‘multi-faceted’ nature of *community*, meaning different things to different people.

The effectiveness of making the quotidian meaningful is debatable, as is the impact of ‘framing’ encounters as ‘performance’ and attributing intent. However, there is no doubt that ‘cultural intervention’, in some instances, improves the lives of people with learning disabilities. ‘Challenging behaviour’ is a gloss for deviancy and, as mentioned previously, is able to subsume deviant behaviour making it less potent by being so categorised. By creating a forum where ‘challenging behaviour’ was less policed, workshops could be seen as acting as a safety valve, a carnivalesque outlet allowing structures of power (such as in day centres) to be maintained. Entelechy sometimes channelled such subversive behaviour into artistic forms such as poetry and drama, although on occasions, the agendas of Entelechy’s group leaders’ took over, leading to them directing the action and diminishing any subversive potential. However, non-compliance, such as ‘getting lost in the audience’ and other discursive devices such as those discussed in Chapter 6, could accumulate into a new aesthetic, allowing empowerment and ownership of the action by the people with learning disabilities: ‘Foucault saw power and resistance as the two sides of the same coin, arguing that the power embedded in one discourse is only apparent from the resistance embedded in another’ (M.Corker 2000:231).

The ROH project drew attention to 'narrative as process' or life as it is lived, overturning the hegemony of the text, with the creation of meaningful expressions (through art) of what it was like to have learning disabilities. The project encompassed a wide range of abilities, and was a pioneering attempt to include non-verbal people by the creation of intersubjectively produced 'auto'/biographies. This project also facilitated in the 'recovery of self post-institutionalisation', giving greater depth to the personhoods of people with learning disabilities who took part in the project. The basic aims of the project - namely 'the cultural recognition' of people with learning disabilities, and the development of sensitive devices for documentation of their lives, many of whom couldn't access textual or verbal communication - could be seen to have been achieved to a high extent.

Entelechy held the belief that all people had a 'self' and that 'self' contained a coherent narrative account of their life, irrespective of whether or not the self was able to communicate with others. The aim of using narrative as a vehicle for the production of a culturally embedded self, however, can be questioned. 'For whom' the documents were produced was also an issue, specifically when they concerned people with profound and multiple disabilities who did not communicate in conventional ways. Two agendas of the ROH project could be discerned; firstly, accessing this narrative using verbal and non-verbal media and communicating this to others involved in the narrator's life; and secondly, individual narratives which became part of a larger project, acting as a testimony to their lives, leading to national dissemination through the creation of training packs. This research showed the creation of entwined ontological and public narratives, as well as access to counter-narratives, by some of the more able

people with learning disabilities. All narratives in the project were treated as ‘authentic’, despite many being a mixture of ‘fact’ and ‘fiction’ and being intersubjectively produced. The informal documentation of the lives of the participants in the project gave carers the ability to attribute the disabled person with a self and sometimes enabled them to prioritise a client’s needs. Narrative, therefore, was shown to be a vehicle through which it was possible to gain a culturally embedded self. The issue of whether such activity was ‘therapeutic’ was raised, that is, how does an experiential group differ from a therapeutic group? Because of their questionable personhood in Western culture, people with learning disabilities frequently have decisions made for them. They are deemed to be more vulnerable and more child-like than the general population and, as such, have their activities regulated by others. It is a fact that many such people have had traumatic lives. The question which is in need of an answer, however, is how should society respond to this large group of marginalized people, many of whom have only fairly recently ‘returned’ to *the community*? Because of the perceived risks inherent in ‘stirring up’ the past for these people, many possible expressive avenues are side-stepped. This has led to a position where it is difficult to conceive of people with learning disabilities taking part in creative activity which is non-therapeutic. Questions of emotional support, responsibility and confidentiality are pertinent. Entelechy’s work on this project was unique and pioneering, attempting to address such questions and, in the process, taking some risks.

The work of Entelechy could, perhaps, be seen as part of the movement termed ‘avant garde’¹⁵⁸, in that it questioned basic assumptions. In its endeavours to allow people with learning disabilities to be incorporated into new aesthetics, Entelechy used methods which could be construed as controversial and sometimes contradictory. The ‘controlled anarchy’ allowed in some workshops was seen as a life-affirming form of release of benefit to the participants. In contrast, some supposedly spontaneous events were, in fact, tightly controlled and orchestrated to allow the agenda of a facilitator to filter through. Working with people with profound and multiple disabilities inevitably requires a flexible and sensitive approach, which has to be continually appraised. In their search for new meeting grounds between facilitators and participants it was never in question that the welfare of those taking part in their projects was always Entelechy’s first priority.

ii) Suggestions for Future Research

This research has highlighted the need for dialogue between people of very differing abilities, facilitated here by the use of ‘the arts’. To prevent people with learning disabilities remaining in a cultural wilderness, such work needs to be expanded into other areas of social life. Sensitive areas which are frequently sidestepped in research with this sector of the population, such as sexuality and intimacy, need to be approached from new angles which neither exploit nor infantilise those concerned. Cultural discourses such as ‘rationality’ and ‘normality’ need to be continually

¹⁵⁸ See Appendix XIV

questioned and challenged, as I have tried to do in this research, revealing the deeply embedded assumptions, both social and cultural, about this group of people.

A further issue which needs to be developed is that of the actual practice of research with people who have learning disabilities. My research dealt with a very heterogeneous group of people with widely differing abilities, some of whom could participate in research with a high degree of 'informed consent', whereas others had no understanding of what 'research' actually meant. Even with people who had a high degree of understanding, the fact that I was a researcher was frequently forgotten, and the research relationship needed to be constantly re-negotiated. What seemed very evident from the research with more able people was that there existed a strong desire to share experiences with 'the public', to put across their points of view with regard to how they see themselves and how they wished to be treated. They were very aware that their lives had been (and still largely were) constrained and curtailed by other more powerful agencies (social workers, doctors, care managers etc.), and welcomed the opportunity to express themselves through aesthetic means (including the use of narratives). Collaborative research with people who have learning disabilities can be seen as an ideal, but is quite hard to achieve when the informants have profound and multiple disabilities, and do not use conventional language or other forms of shared communication. Additionally, their presumed vulnerability can act as a barrier in research, with paid carers and kin being suspicious of the motives of researchers. One possible avenue explored here, that is, the use of aesthetic activity to create meeting grounds between differing worlds, could be developed further. The fusion of

‘performance’ and the ‘everyday’, as in Entelechy’s practice, creates a fertile ground for the exploration of such possibilities.

Appendix I

The following provides a breakdown of group membership of four weekly groups attended, making a total of 41 people. It is difficult to quantify the number of informants involved in the ROH project, but I estimate the figure to be 100. Additionally, many of my informants were day centre users who were not officially part of the groups. On top of this were groups which I occasionally attended such as 'Through the Door', involving approximately 15 people. Then there were 'one-off' projects, training activities, and casual visits to people's homes where I met their housemates, some of whom turned into informants, totalling approximately 500 people (with and without learning disabilities, including carers, family members, artists, and interested others).

The 'Disability diagnosis' column is based on terms used by care workers and non-disabled members of Entelechy.

Ambient Jam - Group Membership January 1997 - December 1998

| | Gender | Age | Ethnic Origin | Disability |
|---|--------|-----|----------------|---|
| A | F | 36 | White British | Blind & Deaf – Rubella damage |
| B | M | 34 | White British | Cerebral palsy and profound learning disabilities |
| C | M | 29 | White British | Cerebral palsy and profound learning disabilities. Visually impaired. |
| D | F | 31 | Afro-Caribbean | Cerebral palsy and autism |
| E | F | 38 | White British | Blind with profound learning disabilities |
| F | M | 36 | White British | Elective mute. Tactile defensive. Restricted mobility due to accident |
| G | M | 24 | White British | Cerebral palsy and profound learning disabilities |
| H | F | 50 | White British | Cerebral palsy, arthritis and profound learning disabilities. |

Weaver - Breakdown of Group Membership September 1997 - December 1998

| | Gender | Age | Ethnic origin | Disability |
|---|--------|-----|------------------------|--|
| A | M | 25 | Colombian | Unspecified learning disability |
| B | F | 30 | White British | Spina Bifida and moderate learning disabilities |
| C | M | 28 | White British | Down's Syndrome |
| D | F | 34 | White British | Unspecified learning disabilities, and mental health difficulties. |
| E | M | 32 | Indian | Fragile X Syndrome |
| F | M | 30 | White British | Unspecified learning disabilities |
| G | F | 60 | White British | Unspecified learning disabilities |
| H | F | 59 | White British | Down's Syndrome |
| I | F | 28 | Chinese | Down's Syndrome |
| J | M | 26 | Chinese (brother of I) | Down's Syndrome |
| K | F | 36 | White British | Down's Syndrome |
| L | M | 33 | White British | Autism |
| M | M | 34 | White British | Down's Syndrome |
| | | | | |

Membership of the Weaver group fluctuated a lot during the period of my research, partly because the group was very permeable, picking up extra members when other day centre activities were cancelled. Also, some people attended college courses, and other day centre activities on a sporadic basis.

The Diamond group - Breakdown of Membership September 1997 - July 1998

This was a group for people with profound and multiple disabilities run in the Diamond day centre. The group folded in July 1998 due to withdrawal of funding by statutory services, who were responsible for running the day centre.

| | Gender | Age | Ethnic Origin | Disability |
|----------|--------|-----|---------------|--|
| A | M | 62 | White British | Unspecified moderate learning disabilities. Blind. Some hearing impairment. He was verbal and joined the group 'by mistake' – he continued to attend the group until he fell ill and died in 1998. |
| B | M | 64 | White British | Paraplegia. Unspecified profound learning disabilities |
| C | F | 25 | Somalian | Unspecified profound learning disabilities |
| D | F | 35 | White British | Down's Syndrome (non-verbal) |
| E | F | 33 | White British | Cerebral palsy and unspecified profound learning disabilities |
| F | M | 36 | White British | Autism and cerebral palsy |
| G | M | 24 | White British | Cerebral palsy and unspecified learning disabilities |
| H | F | 22 | White British | Cerebral palsy and unspecified profound learning disabilities. Visually impaired. |

Crafting Our Memories - Breakdown of Attendance between September 1997 and December 1998

| | Gender | Age | Ethnic Origin | Disability |
|---|--------|-----|---------------|--|
| A | F | 61 | White British | Mild learning disabilities. Mental health problems. |
| B | M | 72 | " | Moderate learning disabilities |
| C | M | 76 | " | Moderate learning disabilities and visual impairment due to a stroke |
| D | M | 70 | " | Moderate learning disabilities |
| E | M | 69 | " | Moderate learning disabilities. Cerebral palsy |
| F | M | 75 | " | Moderate learning disabilities. Cerebral palsy. |
| G | M | 71 | " | Moderate learning disabilities. Mental health problems. |
| H | F | 68 | " | Moderate learning disabilities. Mental health problems. |
| I | F | 68 | " | Down's Syndrome |
| J | F | 65 | " | Mild learning disabilities |
| K | M | 58 | " | Autistic |
| | | | | |

Appendix II

Classification of 'Mental Retardation' (learning disability)

Many efforts have been made throughout the twentieth century to classify mental illness, learning disability and other disorders associated with the mind. For example, in 1939, the World Health Organisation (WHO) added 'mental disorders' to the 'International List of Causes of Death':

In 1948 the list was expanded to become the *International Statistical Classification of Diseases, Injuries, and Causes of Death* (ICD), a comprehensive listing of all diseases, including a classification of abnormal behavior. Although this nomenclature was unanimously adopted at a WHO conference, the mental disorders section failed to be widely accepted. Even though American psychiatrists had played a prominent role in the WHO effort, the American Psychiatric Association published its own *Diagnostic and Statistical Manual* (DSM) in 1952.

Davidson and Neale 1998: 55-6

In the late 1960s the WHO put forward a more widely accepted classification system. The American DSM system was similar to the WHO, but general consensus did not exist. After further research and consultation, DSM-IV was published in 1994, which aimed to include controversies, problems, and possible solutions concerning the various diagnoses. This is the classification system currently in use by the majority of Western mental health professionals, and includes classifications of 'mental retardation' (learning disability). 'Mental Retardation' is defined in DSM-IV as: '(1) significantly subaverage intellectual functioning along with (2) deficits in adaptive behavior and (3) occurring prior to age eighteen'. (ibid: 424). 'Intelligence' is measured using 'aptitude tests' or IQ tests, testing criteria believed by psychologists to constitute 'intelligence' such as:

Language skills, abstract thinking, nonverbal reasoning, visual-spatial skills, attention and concentration, and speed of processing. Scores on most IQ tests are standardized so that 100 is the mean and 15 or 16 is the standard deviation ... thus approximately 65 percent of the population receives scores between 85 and 115. Those with a score below 70 are two standard deviations below the mean of the population and are considered to have "significant subaverage general intellectual functioning".

Ibid.: 80

This sector, constituting approximately 3 per cent of the population, is regarded as ‘mentally retarded’. Factors which may affect the score such as cultural, linguistic and sensory or motor limitations have fairly recently come to be taken into account when such tests are given. The second criteria of ‘adaptive functioning’ refers to the competent accomplishment of tasks appropriate to the age of the individual when assessed; for example, in the case of a child, the ability to dress themselves and use a toilet, and for an adult, the ability to support themselves and have social responsibilities. Davidson and Neale refer to American tests which assess this, such as the American Association of Mental Deficiency Adaptive Behavior Scale (ABS) (Nihira et al., 1974) and the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). The third criteria, i.e. onset in childhood, is aimed to preclude traumatic injuries and illnesses later in life which affect ‘intelligence’ and ‘adaptive behavior’.

The DSM-IV recognises four levels of ‘mental retardation’:

Each corresponding to a specific subaverage range on the far left of the normal distribution curve of measured intelligence ... the IQ ranges are not the sole basis of diagnosis; deficiencies in adaptive behavior are also a criterion of mental retardation. Some persons falling in the mildly retarded range based on IQ may have no deficits in adaptive behavior and thus would not be considered mentally retarded. Usually the IQ criterion is applied only after deficits in adaptive behavior have been identified.

(ibid: 426)

The ‘four levels’ are as follows (listed in Davidson and Neal 1998, based on the criteria of American Psychiatric Association 1994 and Robinson and Robinson, 1976):

- **Mild Mental Retardation (50-55 to 70 IQ).** About 85 percent of all those who have IQs less than 70 are classified as having **mild mental retardation**. They are able to function to a high degree, attending mainstream education and holding down low skilled jobs, perhaps in sheltered workshops. They may need practical support handling finances.
- **Moderate Mental Retardation (35-40 to 50-55 IQ).** About 10 per cent of those with IQs less than 70 are classified as having **moderate mental retardation**. Brain damage and other pathologies are frequent. Many are institutionalized, but most live dependently within the family or in supervised group homes.

- **Severe Mental Retardation (20-25 to 35-40 IQ).** Of those with IQs less than 70, about 3 to 4 per cent come under the category of **severe mental retardation**. These people commonly have congenital physical abnormalities and limited sensorimotor control. Most require constant aid and supervision. Severely retarded adult may be friendly but can usually communicate only briefly on a very concrete level.
- **Profound Mental Retardation (below 20-25 IQ).** One to two per cent of retarded people are classified as having **profound mental retardation**, requiring total supervision and often nursing care all their lives. Most have severe physical deformities as well as neurological damage and cannot get around on their own. The profoundly mentally retarded have a very high mortality rate during childhood.

Appendix III

Advocacy

Entelechy ran a 'Citizen Advocacy' project alongside their artistic activities. Approximately eight people from the local area volunteered to be partnered with a person with learning disabilities whom, it was felt, needed an advocate. I did not take part in this project, largely due to the fact that some very sensitive issues were involved, including ethical issues of confidentiality. Much of this project entailed challenging the efficacy and quality of services for people with learning disabilities, assisting this group to make complaints about their treatment:

Advocates have ... supported their partners to challenge particular practice within learning disability services ... within services it may be difficult for individual workers to support the people they work with to make a complaint about the services that they receive. There are conflicts of loyalty between colleagues and 'service users'. This often leads to real or imagined concerns of being victimised or 'rocking the boat.' Citizen advocates have an important role working independently alongside other service developments supporting people to have greater choice and management of their lives. (Pam Martin, Advocacy Programme co-ordinator for Entelechy, from Entelechy document).

Volunteer advocates were also appointed by Entelechy to support a person with learning disabilities to engage in social activities:

Without the support of an advocate it would have been very easy for some people to loose touch with established networks of friends. Advocates are supporting their partners to maintain their social lives and maintain opportunities for choice (ibid.).

According to David Slater, 'Citizenship' entails 'the exercise of empathy; the projecting of ourselves into the circumstances of another' (Entelechy document). He asserts that in the 'Citizen Advocacy' programme, Entelechy assists local people to use their own ambitions and expectations as markers for the lives of others.

Appendix IV

Makaton

Makaton is an augmentative communication system used in approximately 30 countries worldwide. It has its origins in a research project in the 1970s, which had the aim of finding a communication system to use with deaf adults who had learning disabilities. It is now widely used as a language and communication programme for a wide range of people who have learning disabilities across Britain:

'The first training course was held in 1976 and since then more than 50,000 professionals and non-professionals have been trained in the UK. There are courses and workshops for parents, carers, teachers, speech and language therapists, other professionals and people working with children or adults with communication difficulties.' (extract from leaflet).

I attended a Makaton training course in the summer of 1997, run by the Makaton Vocabulary Development Project. The programme utilises signs from British Sign Language (BSL), but differs in that only key words are signed in spoken word order, accompanied by normal grammatical speech. The idea is that basic information is given in a very visual way, allowing greater understanding of speech, and hopefully reducing frustration. It has been demonstrated to encourage the development of spoken language:

'The Makaton Vocabulary is a Language Programme which provides a basic means of communication and encourages language development in children and adults with learning disabilities. It comprises a small vocabulary of specifically selected concepts/ideas graded in complexity ... The initial stages introduce the vocabulary required to express basic ideas, and more complex concepts are introduced in the subsequent stages. The vocabulary is generally taught with speech and signs, but if required, speech + signs + symbols may be used in combination ... The use of signs by the child or adult to communicate is similar to the use of natural gesture and follows normal stages of communication development.'

(Extract from Makaton workshop manual).

Appendix V

Foucault and the history of madness:

The treatment of people with learning disabilities followed a similar, but by no means exact, trajectory to those people deemed as 'mad'. Foucault asserts that this period in Europe was characterised by the 'Great Confinement', i.e. the incarceration in asylums of people defined by society as 'mad'. However, others such as Gutting (1989) and Midelfort (1980) challenge the historical accuracy of his arguments. Samson points out though, that Foucault's work is a 'hermeneutic endeavour, emphasising cultural constructions of power and knowledge that are not reducible to material reproduction' (Samson 1995:59). Samson compares Foucault's theories to Marxist approaches to the history of madness, such as Scull's (1977, 1979). Scull suggests that the growing capitalist economy in the nineteenth century produced a need to segregate those people not capable of working, such as paupers, the incompetent and the mad, who were sent to asylums, 'while the able bodied became factory fodder' (Samson 1995:59).

Appendix VI

Itard and Seguin:

Itard's (1798) study of the wild boy of Aveyron initiated the first practical scientific study of both medical and psychological aspects of learning disabilities in Europe. By 1828 his pupil Seguin had established the trainability of these so called 'idiots' in a school founded for them in Paris. By 1840 ... the need for provision for English idiots was recognised by the philanthropist Andrew Reed ... the first English Asylum for idiots was founded at Park House, Highgate.

J.C.Sinson 1993:38

Seguin employed techniques such as modelling and positive reinforcement, which emphasised the importance of sensory stimulation and language. He was also concerned that students should gain practical social skills and learn to live in the community as good citizens. He advocated that institutions should be small and located close to cities. The rationale for the location was to allow the students to visit events such as exhibitions, theatres and meetings which would inspire them and stimulate their interest in the life of the community (Scheerenberger 1983). Since the purpose of these establishments was to train people to live in the community, the education was moral as well as useful. It was designed to make people good citizens (Lazerson, 1975).

A.Jahoda 1995:207

Appendix VII

Welfare State International

An important example of a radical touring company was *Welfare State International* (WSI), which eventually put down roots near the nuclear industry town of Barrow, Cumbria. This anti-establishment performance company, 'has struggled to devise artistic events that neither alienate local people nor compromise their own values. Here is a carnivalesque company forced to contend with the morning after and revealing the community-based direction that a number of European and US street theatres took in the aftermath of 1960s and 1970s activism' (Kershaw 1998:208). Kershaw describes the touring work of WSI in the late 1960s and 1970s as large-scale 'carnivalesque agit prop' (ibid.:209), for example, the staging of *Parliament in Flames* (1976), 'a "community bonfire" for November 5th which featured the destruction of a massive mock-up of the Houses of Parliament' (ibid.) in the North of England. The early 1980s saw a development by WSI of an:

Iconoclastic radical ideology, shaped by a deep opposition to the over-production and consumerism of the developed countries. At root the ideology rested on sympathy for the underdog, inspired by a primitive socialism - a collectivist, egalitarian utopianism that was not afraid to make grand, even visionary, claims for the healing power of creativity and the place of 'poetry' in a healthy culture. However, the anarchic edge to these ideas was honed by a pragmatism which produced, at the macro-level, an acute grasp of contemporary power structures, and, at the micro-level, an engagingly unpretentious commitment to local community activism (Fox 1988).

B.Kershaw 1998:209

Many of the *community* performances and spectacles WSI produced in the 1980s could be interpreted as attacking capitalism, in particular, Thatcherism; and the nuclear-power industry on which the town of Barrow was economically dependent. Such performance work attempted to criticise 'official social organisation by offering the experience of an alternative mode' (Cohen-Cruz 1998:167), merging desire with reality.

Appendix VIII

Further implications and extracts from the Dartington Conference Report 1983

Robert Witkin, a social psychologist at Exeter University, gave the opening address to the Dartington conference, entitled 'Arts in an Individuated Society', which raised several central issues with which Entelechy is concerned. Witkin addressed the problem of the role and meaning of the 'arts' in society. He suggested that there are two central ideas about art in the modern world:

The first emphasises the fact that all of the creative arts - drama, music, art, poetry, dance - make use of languages which are sensuous in feeling; that effect, emotion and feeling is so central to the way artists speak, to the voices they use, that if art ever lapses into a language which ... is philosophical or didactic, or logical or discursive, it loses its essential character... a second idea, which is equally strong ... is that art is, above all, the

province of the individual ... artists must in some way authentically realise, express, initiate, create from their own experience of life and that they must have freedom and autonomy to do this.

Witkin 1983:28

Thus, Witkin suggests, if these two ideas are conjoined, i.e., that 'art' is about 'emotion' expressed by an 'individual', the term 'self-expression' emerges. This, he argues, is very much a modern Western phenomenon, a product of 'individualism', coinciding with the growth of the modern 'rational state'. Instead of the subject matter of artists being prescribed by the Church and royalty, or dictated by tradition, the modern artist was able to use 'his (sic) own persona, his own individuality as his principle resource.' (ibid.: 29). This change was accompanied, Witkin asserts, by the withdrawal of state interest in what he terms 'human values'. Witkin appears to be arguing, therefore, that secularisation is responsible for the creation of an affective private sphere, and that the state no longer plays a part in controlling 'sensuous' life, which, he asserts, has potentially negative consequences.

Drawing on the work of 19th Century theorists, in particular Durkheim, Witkin argues that they were interested in explaining the difference between 'simple' and 'complex' societies. Different types of consciousness were attributed to different societal formations, Witkin suggests, with members of 'simple societies' being characterised as 'mystical', 'religious', 'sensuous', 'emotional' and 'aesthetic'; in opposition to the more 'advanced', 'complex' societies, in which people 'progressed' away from such 'affective' ways of thinking, towards a 'rational', 'calculative', 'analytical', 'impersonal', 'logical, and 'objective' consciousness. This is evidently an oversimplification of Durkheim's ideas about mechanical and organic solidarity, and the phenomenon of 'conscious collective'. In some respects, Witkin's stance resonates with that of Weber, who asserted that 'rationalisation' would lead to the 'disenchantment of the world', with a loss of mystical and sensuous experiences. Weber suggested, however, that if the rational-legal mode of social organisation was taken to extremes, a social system devoid of meaning and 'irrational', imprisoned in its own rational forms, could develop. This is, perhaps, the type of society which Witkin fears has developed, as an agent in its own destruction, unless people can come together under some shared sense of *communitas*. Witkin's concerns, and those of other theatre practitioners at the time, were focused on reconciling sixties and seventies idealism with the harsh realities of the New Right in the 1980s.

Witkin points to a similar idea of developmental 'progress' within the discipline of psychology, in particular the work of Piaget. Children are assumed to be 'sensuous', 'artistic', 'aesthetic', 'mystical' and 'naively realistic'. As they become adults, according to Piaget, they lose these characteristics and become 'objective', 'rational', 'discursive' and 'logical'. This leads Witkin to conclude that 'science' is valued much more highly than the 'arts' in this society, and that the 'arts' are associated with children and 'primitives'. While 'science' has given humans greater control over the natural world, Witkin asserts, the value of the 'arts' is questioned. Witkin's address bears many similarities with the ideas of proponents of 'secularisation' theory in the 1960s, such as Bryan Wilson, who's ideas were based around the perceived decline of 'traditional' *communities* and beliefs due to the process of industrialisation (echoed by Tonnies

suggested transition from *Gemeinschaft* to *Gessellschaft* type relations). The modern individual, according to Witkin, 'is responsible, as never before, for constituting his (sic) awareness of the world, for making his experience of community' (ibid.:33). Witkin argues that developments in twentieth century art and theatre offer:

The elements out of which the individual can constitute a reality which unifies personal and social being but demanding (literally provoking) active construction and participation in constituting that reality. I take this to be as central to Cubism as it is to Brecht. Such an art is poised to arouse a vision which is personally and socially authentic.

ibid.

Witkin concludes by asserting that the individual, instead of being a fragment, is instead 'the whole of the community, realised in one of its aspects, one of its parts' (ibid.). He laments the transition to individualism, reflected in the words of John Donne who opposed the idea that 'the individual can exist who is not the realisation of the whole' (ibid.): "No man is an island, entire unto himself, every man is a piece of the continent, a part of the main."

As has been shown in the main body of the thesis, the participants at the conference believed in creating a sense of 'relatedness', which could be seen in the later work of Entelechy. Examples were given of this sense of 'relatedness' created in practice by theatre groups working in *the community*, a few of which I have selected below as a means of illustration (Taken from Summary Report 1983: 23-24):

a) In hospitals - by establishing better relationships between doctors and patients, between the elderly and those caring for them, and between patients themselves.

**e.g. Het Werkteater, Netherlands
North West Spanner, United Kingdom**

b) In inner city areas where there is racial tension - by working with ethnic minority groups or guest workers using performance to extend understanding and create harmony

e.g. Kroeuzberger Turkische Volksbugne, West Berlin.

c) In small towns - by involving as many as five hundred people or more in developing a local story into a play and by creating over many months a network of relationships between disparate group such as those involved in local industry and their neighbours

**e.g. The Colway Theatre Trust, United Kingdom
Milton Keynes, United Kingdom.**

d) In permanent purpose-built Community Arts Centres in inner city areas - by developing, through a resident group of community artists, all kinds of activities alongside those of theatre

**e.g. Combination at the Albany, United Kingdom
Interaction, United Kingdom and in Europe.**

e) In the streets and open spaces of towns and cities, or in rural areas - by reviving the spirit of community through identifying local concerns and building celebrations around them. By involving people of the locality in the making and in the celebration.

**e.g. La Tartana, Spain
Welfare State International, United Kingdom
C.U.I.F.R.D. Nancy, France**

f) In touring theatre extensively at home and abroad - by working with theatre and the visual arts to inform the majority of the minority group's needs and to strengthen the cultural identity of the minority itself.

**e.g. Piccolo Teatro di Pontedera, Italy
Tukak Theatre, Denmark
International Nieuwe Scene, Belgium
Cardiff Laboratory Theatre, United Kingdom.**

**g) In prison - through the making of highly skilled performances and by the use of a barter technique (whereby a theatre performance is exchanged in kind), enabling the prisoners to glimpse for a moment the spirit of community.
e.g. Odin Theatre, Denmark.**

Appendix IX

Breakdown of Between Two Worlds workshop participants:

Breakdown of people paid to attend workshop

| Workshop 1 | Workshop 2 | Workshop 3 |
|----------------------------|----------------------------|----------------------------|
| Musician – Charles | Musician – Charles | Musician – Charles |
| Arts facilitator – Rebecca | Arts facilitator - Rebecca | Arts facilitator – Rebecca |
| Director – David | Director – David | Director – David |
| Dancer – Siobhan | Dancer – Siobhan | |
| Dancer – Laura | Dancer – Laura | |
| Apprentice – Peter | Apprentice – Peter | |
| Care worker – Paul | Care worker – Paul | |
| Disabled dancer – Jane | Disabled dancer – Jane | Disabled dancer – Jane |
| Disabled musician - Steven | Disabled musician – Steven | Disabled musician - Steven |
| | Managing Director - Enos | Jane's female care worker |
| | Dancer - Kate | Jane's male driver |

Breakdown of participants at the three workshops:

| Workshop 1 | Workshop 2 | Workshop 3 |
|---|--|---|
| Advocacy worker with people who have learning disabilities f | Day centre officer trained as a dance therapist f | A sports and leisure day centre officer at a social services day centre f |
| Dance student f | Residential home manager setting up day services f | Additional needs unit worker working with people who have profound and multiple disabilities f |
| Youth worker for a charity f | Sexuality worker with people who have learning disabilities f | Day centre worker f |
| Day centre officer with people who have learning disabilities f | Dancer attached to Occupational Therapy team f | Day centre worker attached to residential care unit f |
| Dramatherapist, working with people who have learning disabilities m | Administrator in health and music therapy m | Day centre worker m |
| Day services manager for people who have learning disabilities m | Residential care worker f | Worker in independent living project m |
| Residential services worker with people who have learning disabilities f | Day centre manager f | Community team worker, working with people with profound and multiple disabilities f |
| Day centre officer with people who have learning disabilities f | Day centre worker m | Integrated leisure co-ordinator for a learning disability charity f |
| Day centre officer with people who have learning disabilities f | Support worker for people who have challenging behaviour f | Arts administrator for learning disability music project f |
| | Arts project worker with adults who have Down's Syndrome m | |
| | Manager of a group home f | |
| | Day services worker f | |
| | Manager of residential home f | |

| | Percentage working for organisations funded by social and health services | Percentage working for charities | Percentage working in arts only | Percentage working in both arts and social & health services |
|------------|---|----------------------------------|---------------------------------|--|
| Workshop 1 | 70 | 20 | 10 | 10 |
| Workshop 2 | 92.3 | 0 | 8.3 | 25 |
| Workshop 3 | 77.7 | 11.1 | 11.1 | 22.2 |

Appendix X

Dadaism

The technique of how poetry was created in the Weaver group can be compared to the 'automatic writing' of the Dadaists in the early years of the twentieth century:

Arp also tore out scraps of paper (their edges 'drew themselves', without conscious intervention, by being torn) and let them drop on a sheet, fixing them where they fell, thus achieving collages made wholly in accordance with the laws of chance. These procedures were followed in writing by Tristan Tzara, who made poems of arbitrarily scrambled sentences and from words drawn, allegedly at random, from a bag.

R.Hughes 1991:61

Appendix XI

John O'Brien's Five Service Accomplishments (taken from Emerson 1993: 14):

1. Ensuring that service users are *present* in the community by supporting their actual physical presence in the same neighbourhoods, schools, work places, shops, recreation facilities and churches as ordinary citizens.
2. Ensuring that service users are supported in *making choices* about their lives by encouraging people to understand their situation, the options they face and to act in their own interest both in small everyday matters and in such important issues as who to live with and what type of work to do.
3. Developing the *competence* of service users by developing skills and attributes that are functional and meaningful in natural community environments and relationships, i.e. skills and attributes which significantly decrease a person's dependency or develop personal characteristics that other people value.
4. Enhancing the *respect* afforded to service users by developing and maintaining a positive reputation for people who use the service by ensuring that the choice of activities, locations, forms of dress and use of language promote the perception of people with disabilities as developing citizens.
5. Ensuring that service users *participate* in the life of the community by supporting people's natural relationships with their families, neighbours and co-workers and, when necessary, widening each individual's network of personal relationships to include an increasing number of people.

Appendix XII

Crafting Our Memories

The group was run according to the following aims and objectives:

- 1 To create a space for people to be together; a place where people can meet, connect and exchange experiences; a working environment where differences are accommodated.
 - 2 To create an open structure to facilitate people to take part in creative activity with others.
 - 3 To stimulate choice and possibility, as reflected in the range of material employed, the spatial set-up of the room, the number and diversity of participating members (including a skilled art teacher, older people without learning disabilities and arts workers/volunteers interested in this type of engagement).
 - 4 To explore connections between past, present and future.
 5. To strengthen and affirm the individual's sense of self.
- (from p.3-4 Progress Report to Department of Health 1997-98, Mara de Wit).

'Come and share your memories. Remember places where you have lived; things that you have seen and done. Words are not important. We will use paint, paste, paper and many other bits and pieces to make and create things....Pictures and objects that say something about ourselves; stories that we can show and share with others' (from an Entelechy leaflet advertising the group).

Appendix XIII

Fact and fiction in learning disability narrative: the viewpoint of ROH co-ordinator, Mara de Wit:

'I would never try and stop that or try to think "no but really, what happened here?"... when that is painted or acted out or re-entered, I think there is a sort of artistic creative license that would be open to anyone really ... to inhabit all the different or even impossible aspects of themselves ... however, when someone's background is traced and recounted, say, for a care plan or exactly what sort of medication someone needs or to understand more clearly what may have brought about certain fictional stories ... I'm thinking now of Lucy, who at times says 'get off me, get off me' when no one is touching her. In a way she is expressing her past in the present time ... what is there in her past that makes her in the present react like that? It might be then useful to find out the facts around a person's life and see if stories can be correlated ... in many ways we can all tell stories about ourselves in order to make sense of ourselves now, or even how you tell a sequence of events or which elements you highlight, makes it some sort of fiction ... you could even say that medical records would be fiction based on a certain construct of reality ... although there are very clear points of reference that are

absolutely shared, like place, time, year, date, person's name, it all gives more viability to the truth of a story ... working alongside someone with learning disabilities for whom numbers or years or names have no meaning it becomes a quite important complementary role or function for the carer to take that responsibility to track those factual aspects so that other people can relate and recognise them'.

Appendix: XIV

Entelechy and the Avant Garde:

When questioned about Entelechy's relationship to the 'avant garde', David Slater replied:

I don't know whether I'd bother considering the work is avant garde or whether we need to or not ... part of that is because of the way up until fairly recently the work has been funded, where there has never been that pressure to conform with conventional expectations in terms of producing an aesthetic or whatever ... where it aspires to work with people at the edge of their experiences and brings together people in encounters where they feel awkward or uncomfortable, or uneasy or moving through that ... sometimes where the work is most interesting is where it's moving into new territories, certainly, where as practitioners we are uncertain of where it goes ... now if that is a relationship to the avant garde then, yes ... we went to a conference once organised by the Institute of Contemporary Art, called 'Avant Garding the Avant Garde' ... we just talked about the work we did ... and the terms of reference of the conference made no sense to any of the people we were working with so its not a context we've necessarily had to fit in with.

Poignantly, an elderly woman from the local *community* in Rotherhithe, who had been involved in several of Entelechy's productions, was presented at the above mentioned ICA event with an award for her contribution to the 'avant garde'. She was given a 'trophy', which took the form of an exploded can of foam. Apparently, she was not impressed, and gave the can to David, where it remained high on a shelf in Entelechy's offices gathering dust.

Glossary

Facilitators – Entelechy’s arts practitioners and animateurs.

Members – The term used by Entelechy facilitators to refer to the people with learning disabilities with whom they worked.

Services – Referring to statutory service provision for people with learning disabilities.

Service User/Client – Interchangeable terms used within statutory services to refer to people with learning disabilities.

‘The Drone’ – A trance like state, akin to *communitas*, achieved in some workshops through the use of music and movement techniques.

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